

THE UNIVERSITY OF HULL

Family Caregiver Responses to Dementia

being a Thesis submitted for the Degree of
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by

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Overview

This portfolio thesis consists of three parts:

Part one is a systematic review of extant literature aiming to present an understanding of the factors associated with psychological wellbeing amongst family caregivers of individuals with dementia. Previous work has been limited in its coverage of care-recipient, caregiver and systemic associates with spousal and family caregiver as well as the constructs of psychological wellbeing measured. After a systematic search of the literature and application of inclusion and exclusion criteria, 11 studies were included for review. Findings were compared across studies and methodological quality evaluated. The findings were compared to theories presented in existing models of caregiving and future research and clinical implications discussed.

Part two is an empirical paper focusing on care-recipient challenging behaviour and its relationship with spousal/family caregiver attributions, emotional responses and willingness to help. A gap in the literature was identified in relation to whether Weiner's (1985) cognitive-emotional model of helping behaviour could be applied to the help-giving behaviour of family caregivers of individuals with dementia. Fifty-two spousal and family members providing care for an individual with dementia at home participated in a cross-sectional, quantitative study. Regression analyses were used to test the suitability of a mediator model to caregiver willingness to help. The results did not support the model tested. However it replicated findings from previous work, suggesting important roles for optimism and sympathy. It was not possible to discern precise functions from the present findings. Implications for future research and within the clinical context were discussed.

Part three comprises of the appendices in order to supplement parts one and two, and a reflective statement describing the experience of conducting the research project culminating in this portfolio thesis.

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Part One

Systematic Literature Review

Factors associated with psychological wellbeing in family caregivers of individuals with dementia: a systematic review of the literature

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Factors associated with psychological wellbeing in family caregivers of individuals with dementia: a systematic review of the literature

ABSTRACT

Background: Previous empirical studies and reviews have investigated the links between Behavioural and Psychological Symptoms of Dementia and caregiver wellbeing, with a large focus on caregiver burden. A number of additional consequences of dementia and constructs of wellbeing have been posited. There is a growing population of spousal and family caregivers of individuals with dementia (IWD), however a lack of a comprehensive review of the wider processes involved and their interaction with caregiver wellbeing. The present paper aimed to systematically review extant literature on factors associated with psychological wellbeing amongst family caregivers of IWD.

Methods: A systematic review of PsychInfo, MEDLINE and CINAHL electronic databases and a manual search of the Journal of Dementia was conducted. Peer-reviewed journal articles available in English and published between January 2002 and December 2011 were considered for inclusion. Case-studies, intervention and validation studies, care-recipients with young-onset dementia and populations from non-western cultures were excluded from analysis. Analysis employed a qualitative narrative method.

Results: Eleven papers were included for review. Three themes were extracted: Care-recipient variables, caregiver variables and family/systemic variables. These were further divided into 6 sub-themes: care-recipient cognitive and behavioural disturbances; caregiver appraisals; caregiver coping style; familism and dysfunctional thoughts; marital idealisation; and engagement in activities.

Conclusion: Partial support was found for Pearlin *et al.*'s (1990) stress-process model. Greater weighting was given to caregiver coping and appraisals, care-recipient behavioural disturbances, and marital idealisation due to methodological quality. Further research and employment of longitudinal design may facilitate more firm conclusions.

Key words: Dementia; family; caregivers; wellbeing; review

Introduction

Dementia is the progressive decline of memory, judgement, thinking, emotional control, social behaviour and motivation associated with gradual brain cell death (WHO, 1992), and is rising in prevalence within a progressively ageing population within the United Kingdom (Knapp *et al.* 2007). Following a diagnosis of dementia an individual can expect, on average, to live a further 3-9 years (Ganguli, Dodge, Shen, Pandav & DeKosky, 2005; Helzner *et al.*, 2008; Larson *et al.*, 2004) during which time they will invariably need someone to support them. The proportion of care received by an individual with dementia (IWD) that is informal and provided by a family caregiver, usually a spouse or close family member, is increasing and now constitutes the majority of their support (McDaid, 2001; Boyle 2010).

Providing informal care has a number of potential consequences for the caregiver. These can be objective including loss of time and finance (Langa *et al.*, 2001) or subjective, including positive or negative consequences (Boerner, Schulz & Horowitz, 2004). The positive aspects of providing care for an IWD as a spouse or family member are less explored in the literature but are thought to include: positive affect (Pinquart & Sörensen, 2003); caregiver satisfaction (Nolan, Grant & Keady, 1996); companionship, gratification and enjoyment (Cohen, Colantonio & Vernich, 2002); mastery, personal growth and self-acceptance (Kramer, 1997).

The more extensive evidence base surrounding negative consequences indicates that providing informal care for an IWD is associated with: depression and decline in health self-perception (Schulz, O'Brien, Bookwala & Fleissner, 1995); increased mortality (Schulz & Beach, 1999); emotional burden (Ballard, Lowery, Powell, O'Brien & James, 2000); and reduced quality of life (QOL; Vellone, Piras, Talucci & Cohen, 2008). A number of these consequences fall into the category of psychological wellbeing, which for the purposes of this review will be operationalised in hedonic terms, namely pleasure attainment and emotional pain avoidance (Ryan & Deci, 2001).

Psycho-social models of caregiving highlight factors that are likely to be associated with such potential outcomes. Corcoran (2011), for example identifies how caregiving style can influence caregiver wellbeing, with a more

'balanced' style (paying attention to both the needs of the caregiver as well as care-recipient) and an 'advocating/problem-solving style' providing buffering effects against psychological distress (Di Mattei *et al.*, 2008; Knussen *et al.*, 2008; Corcoran, 2011).

One model used to understand the process of care-giving and its effects upon the caregiver is Pearlin, Mullan, Semple and Skaff's (1990) stress-process model. Based on transactional approaches to stress (see Folkman and Lazarus, 1980, 1990), this model posits that caregiver outcomes including psychological wellbeing and propensity to help are influenced by a process involving: background and contextual factors; primary stressors linked to the care-recipient and changes in relationship with the care-recipient; secondary stressors associated with consequent changes to the system around the caregiver and their own identity. The relationship between these factors and caregiver outcome is said to be mediated by caregiver appraisals, coping style, self-efficacy and social support. Folkman and Lazarus (1980, 1990) propose that an emotion-focussed coping style and a greater sense of mastery buffer against stress and increase caregiver wellbeing when the stressor is not easily modifiable which may be applicable to caring for IWD.

Testing such models of caregiving and burden and identifying factors that are associated with and/or predict wellbeing in caregivers has important conceptual and clinical implications such as informing how services can improve the support they provide for family caregivers throughout the caregiving process. Whilst numerous studies have addressed such issues, there have been few attempts as yet to review and synthesise evidence in this field.

The most relevant systematic review in this area had a narrow focus on the effects of the Behavioural and Psychological Symptoms of Dementia (BPSD; see Finkel, Costa & Silva, 1996) and its relationship with burden of care (Black & Almeida, 2004). The authors concluded that there was mixed support that greater BPSD is predictive of caregiver burden and that future research should focus on outcomes with more clinical application, such as depression or anxiety.

On the basis of conceptual models of caregiving (e.g. Pearlin *et al.*, 1990) it is reasonable to ask whether there are a broader range of dementia-related factors (in addition to BPSD) which influence the wellbeing of family caregivers. These may include factors specific to the caregiver and their context

which impact upon wellbeing such as coping style (Folkman & Lazarus, 1980, 1990). The model presented by Pearlin *et al.* (1990) would suggest that family caregiver wellbeing is subject to a number of interacting factors including, care-recipient, caregiver and systemic variables. Additionally, existing work in this field frames caregiver wellbeing with reference to various outcomes or constructs, including (but not limited to) affect, burnout, QOL and depression, as well as caregiver burden.

To date, there has been no synthesis of contemporary studies that have investigated a wider range of factors associated with dementia and their consequences for the wellbeing of family caregivers, as defined by various different outcomes and constructs. This presents a significant gap in the existing literature as this area is one of clinical and research relevance for a number of reasons. Firstly, the prevalence of family caregivers in dementia is growing and many are likely to require support from statutory and voluntary services (McDaid, 2001; Boyle 2010). Secondly, there is a lack of a balanced exposition of how different dimensions of psychological wellbeing are affected by providing care for a family member with dementia. Thirdly, this construct of caregiver wellbeing may link to the caregiving behaviours provided toward the IWD, thus may be of relevance to the care-recipient as well as caregiver (Corcoran, 2011).

Consequently, the present paper aims to expand upon the limited applicability of Black and Almeida's (2004) review and presents a systematic review of the literature surrounding specific factors associated with psychological wellbeing amongst family caregivers of IWD, based on the following questions:

1. What constructs of psychological wellbeing are observed as varying when providing care at home for a family member or spouse with dementia?
2. Which factors specific to being a family caregiver of an IWD are most strongly associated with these variations in psychological wellbeing?

Aims

1. To conduct a systematic review of studies into factors associated with psychological wellbeing amongst family caregivers of IWD.

2. To critically evaluate the methodology of the reported papers.
3. To evaluate what conclusions can be drawn regarding the factors associated with psychological wellbeing amongst family caregivers of IWD and identify potential future areas of research.

Method

A systematic search of published literature surrounding the psychological wellbeing of family caregivers of IWD was undertaken. This included searching, screening, synthesis and analysis.

Search strategy

Three electronic databases: *PsycINFO*, *MEDLINE*, and *CINAHL Plus with Full Text* were searched in January 2012. The following search was entered into these databases:

[response*] OR [affect] OR [distress] OR [burden] OR [wellbeing] OR [well-being] OR [well being] OR [quality of life] OR [QOL]

AND

[carer*] OR [caregiver*] OR [care giver*] OR [care-giver*] OR [caring]

AND

[dement*] OR [Alzheimer*]

AND

[relat*] OR [famil*] OR [filial] OR [spous*]

AND

[predict*] OR [factor*] OR [determin*] OR [mediat*] OR [moderat*] OR [influenc*] OR [correlat*]

These search terms were selected following a preliminary search of key articles found by the author and a manual search of the terminology used within the reference lists of these articles. Search terms were applied to titles and abstracts of articles available in the English language between January 2002 and December 2011 (inclusive). This was to avoid the inclusion of papers

covered in the Black and Almeida (2004) review of BPSD and family caregiver burden which included research between 1990 and 2001 and therefore ensure that conclusions drawn from this review are representative of the current context of dementia and growing population of family caregivers.

In order to increase specificity, limiters were applied to the searches carried out within each database (see Figure 1). Search results also had to meet specific inclusion criteria (see below) to ensure quality and relevance to the review question. Finally, the reference lists of studies meeting inclusion criteria and of sufficient quality were hand searched and a manual search of papers published in the *Journal of Dementia* (Keady, Harris & Wilkinson, 2002) between January 2002 and December 2011 was also carried out.

Inclusion criteria and quality control

The initial search yielded 1477 results which was reduced to 302 with the application of limiters. Article abstracts were then screened and selected for inclusion if they met the following inclusion criteria:

- i. Literature must be a peer-reviewed journal article.
- ii. Article must be written or available in English language (as translation may cause researcher bias).
- iii. Published between January 2002 and December 2011.
- iv. Care-recipient must have a diagnosis of dementia from a certified professional.
- v. Care-recipient must be a community-dweller.
- vi. Article must use a validated measure of clinically-relevant psychological wellbeing as discussed in the introduction (including measures of affect, distress, burden or QOL).
- vii. Journal article must meet quality assessment criteria (see below).

Quality assessment was carried out in order to ensure that each paper met a minimum standard for inclusion in the review and to facilitate evaluation of the conclusions that could be drawn from each study, based on their validity, reliability and generalisability. A checklist was developed and adapted from previous quality checklists developed by Downs and Black (1998), Vandenbroucke *et al.* (2007) and Harden *et al.* (2004). This bespoke quality

checklist was developed to allow particular sensitivity to measures used and participant characteristics, as these qualities may determine what conclusions can be drawn from each study and the representativeness of their findings respectively. This is important as this review included papers examining a number of different constructs of psychological wellbeing, using a number of different measures. Selected papers were required to meet a minimum quality threshold of no fewer than 6 points out of a possible 20 (see Appendix C). Articles were excluded from the review if the following criteria applied:

- i. They were a dissertation.
- ii. They were a case study.
- iii. If the sample of caregivers included individuals who were not a spouse or family member.
- iv. If the care-recipient had co-morbid diagnosis of a learning disability.
- v. If dementia care-recipients include non-dementia/physical disability/no disability at all persons.
- vi. If care-recipients were younger than 65 years of age as early-onset dementia may have different psychological correlates.
- vii. The sample population was from a non-western culture as dementia prevalence is lower in non-western cultures (Chen, 2004) and traditionally family members in non-western cultures assume total responsibility and acceptance of care services is discouraged (e.g. Park, 2002).
- viii. Wellbeing (as defined above) is not the dependent variable.
- ix. Primary objective of the study is to validate/evaluate the psychometric properties of a measure of psychological wellbeing.
- x. Intervention studies.

Data extraction

Data were extracted from included studies by the author using a table developed by the author (Appendix D). This data included the citation, main

study aims, participant characteristics, main measures used, results including *p* values and emergent themes. This provided the basis for collating and conducting a narrative synthesis of the findings of included studies.

Data analysis

Key factors were generated by identifying which emergent themes (elicited using the data extraction form) were common across studies, and the fewest amount of these themes which could account for all the papers' findings. A qualitative narrative was then used to compare the findings within and between each section. This helped to prevent inherent researcher bias caused by the transformation of data which would be required for a quantitative meta-analysis, given the range of measures used across papers.

Results

After manual screening of titles and abstracts using the inclusion and exclusion criteria described above, 64 articles were retained. The full texts of the remaining 64 studies were accessed and the application of inclusion and exclusion criteria to these identified 11 studies for inclusion in the review. The main reasons for exclusion were: care-recipients under the age of 65 (27); sample came from a non-western culture (9); no use of a validated measure of psychological wellbeing (6); there was no diagnosis of dementia from a certified professional (5); the paper was a validation study (6); the paper was a case study (4); or care-recipients in residential or institutional settings (2).

Hand-searching the reference lists of included articles identified no further studies which met the criteria for inclusion in the present review. A manual search of articles published in the *Journal of Dementia* (Keady, Harris & Wilkinson, 2002) between January 2002 and December 2011 also identified no further studies for inclusion. For clarity, the article selection process is illustrated in Figure 1.

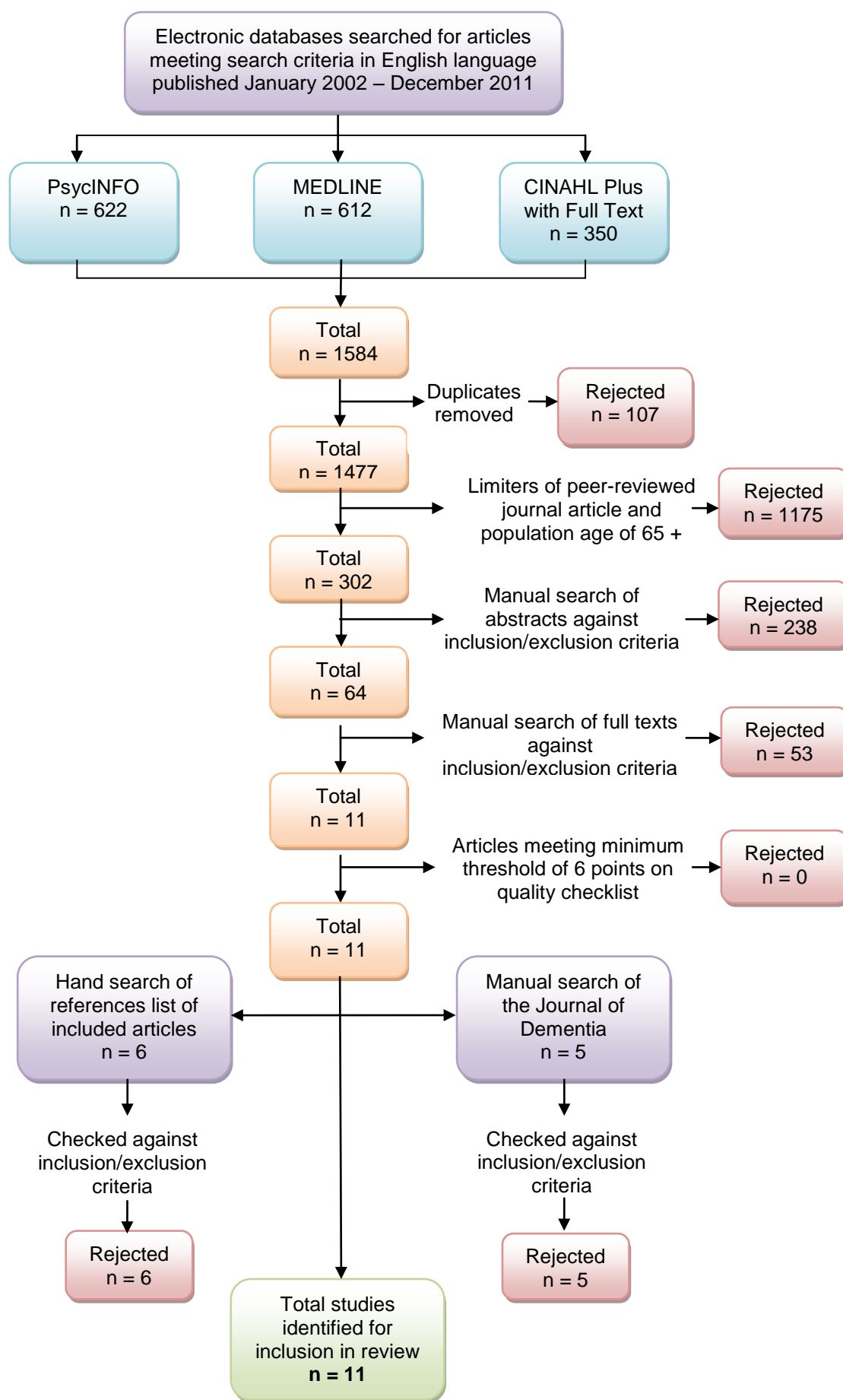


Figure 1. Article selection process

Characteristics of included studies

Studies selected for this review are presented in Table 1.

The majority of studies (5) were conducted in the USA (Butt *et al.*, 2002; Mausbach *et al.*, 2006; Mausbach *et al.*, 2008; Mausbach *et al.*, 2009; Fisher *et al.*, 2011). Two studies took place in Canada (Gottlieb & Rooney, 2004; O'Rourke *et al.*, 2011), one study was from Italy (Aguglia *et al.*, 2004), one from Spain (Losada *et al.*, 2010) and one from the UK (Searson *et al.*, 2008). One study took participants from Sweden, Spain, UK and USA (Bergvall *et al.*, 2011).

A total of 2130 participants took part in the 11 studies. Participants tended to be spousal caregivers, with this population constituting the entire sample for 5 of the 11 studies (Butt *et al.*, 2002; Mausbach *et al.*, 2006; Searson *et al.*, 2008; Mausbach *et al.*, 2009; O'Rourke *et al.*, 2011). The remaining studies used mixed samples of spousal and inter-generational caregivers. Care-recipients had a diagnosis of Alzheimer's disease in five of the studies (Butt *et al.*, 2002; Mausbach *et al.*, 2006; Mausbach *et al.*, 2009; Bergvall *et al.*, 2011; O'Rourke *et al.*, 2011). The remaining studies featured care-recipients who had either Alzheimer's disease, Vascular Dementia, Dementia with Lewy Bodies or Parkinsonian dementia.

The majority of studies utilised a quantitative, cross-sectional design apart from Mausbach *et al.* (2008) who used a quantitative time-series design, and O'Rourke *et al.* (2011) who used a quantitative longitudinal design. All studies were non-experimental in their approach.

A range of constructs relating to caregiver psychological wellbeing were investigated across the 11 studies. Burden was measured in five of the studies. Depression was measured in five of the studies. Affectivity was measured in four of the studies. Anxiety was measured in one study. Life satisfaction was measured in one study. Finally, general mental health was also measured in one of the studies (see Table 1).

Table 1. Study design, sample characteristics and findings

| Study (Country) | Study Aim(s) | Sample | Design | Main Variables/ Measures | Findings (Quality Rating) |
|--|--|--|---------------------------------|--|---|
| Aguglia <i>et al.</i> , 2004 (Italy) | Investigate relationship between caregiver levels of stress and sociodemographic variables, care-recipient's level of cognitive impairment and independence in ADLs. | 236 family caregivers. Female: 66.7% Mean age (male): 64.7 Mean age (female): 61.1 Spouses: 41.4% Children: 46% Other: 12.6% | Quantitative Cross-sectional | Level of cognitive impairment: MMSE ADLs: IADL & ADL Caregiver burden: CBI Caregiver anxiety and depression: BSI | High cognitive impairment associated with high caregiver anxiety, depression and burden. Lower ADL associated with greater caregiver anxiety, depression and burden. (8) |
| Bergvall <i>et al.</i> , 2011 (Sweden, Spain, UK & USA) | Investigate direct and indirect associations between caregiver burden and care-recipient cognitive impairment, ADL and behavioural disturbance as well as time spent providing care. | 866 family caregivers to Alzheimer's patients. <u>Sweden</u> n = 182; mean age: 70.2; 55.5% female; 76.1% spouses; 18.9% | Quantitative Cross-sectional | Level of cognitive impairment: MMSE ADL: DAD Behavioural disturbance: NPI-Q Caregiver burden: ZBI Resource utilisation: RUD-Lite | Care-recipient level of cognitive impairment, ADL and behavioural disturbances all significantly associated with caregiver burden (except cognitive impairment level in Spain). Time spent providing care positively correlated with caregiver burden (except in USA). |

children; 5%
other.

Spain

n = 225; mean
age: 60.6; 71.4%
female; 46.4%
spouses; 45.5%
children; 8.1%
other.

UK

n = 247; mean
age: 71.3; 61.2%
female; 76.5%
spouses; 19%
children; 4.5%
other.

USA

n = 212; mean
age: 66.9; 66.5%
female; 63.7%
spouses; 27.4%
children; 6.1%

Association between ADL and
caregiver burden partly mediated by
time spent providing care.

Behavioural disturbance has stronger
effect on caregiver burden than ADL
and this effect is direct and not
mediated by time spent providing
care.

(17)

| | | | | | |
|---|--|--|---------------------------------|---|---|
| Butt <i>et al.</i> , 2002 (USA) | Investigate relationship between caregiver negative affectivity and coping style; Examine any differences between self-report and informant report provided by adult children. | other. 90 spousal caregivers of Alzheimer's patients. Female: 51% Mean age: 68.4 39 adult children of caregivers. Female: 67% | Quantitative Cross-sectional | Caregiver self report of negative affectivity: SEDS subscale of WAI Informant report of caregiver negative affectivity: NEO-FFI Pruchno & Resch's (1989) coping measure | Higher levels of negative affectivity associated with greater use of caregiver emotion-focussed coping style and less use of acceptance coping. Negative affectivity not related to use of instrumental coping. No significant difference between self-report and informant report of negative affectivity. (16) |
| Fisher <i>et al.</i> , 2011 (USA) | Investigate the associations between family caregiver burden and depression and care-recipient ADL, cognitive impairment and behavioural disturbances. | 120 family caregivers. Mean age: 60.1 Female: 70.6% Spouses: 23.3% Child: 55% Other: 21.7% | Quantitative Cross-sectional | Caregiver depression: CES-D Caregiver burden: Items from Caregiver Health Effects Study (Schulz & Beach, 1999) Behavioural disturbance: NPI-Q Cognitive impairment: CDR, DSRS & MMSE | Caregiver burden and depression significantly associated with behavioural disturbance. No significant association between degree of cognitive impairment and burden and depression. (18) |

| | | | | | |
|---|--|---|-------------------------------------|--|---|
| Gottlieb & Rooney 2004 (Canada) | Investigate relationship between family caregiver's evaluation of coping effectiveness and their affect and mental health. Determine whether coping effectiveness has direct effect or whether it is moderating variable between affect and mental health and caregiver outcome expectancy or coping. | 141 family caregivers. Mean age: 61 Female: 74% Spouses: 36.9% Inter-generational caregivers: 63.1% | Quantitative Cross-sectional | Caregiver mental health: SF-36 Caregiver positive and negative affect: ABS Memory and behaviour problems: R-MBPC Coping behaviours and effectiveness: 4 sub-scales from Gottlieb and Gignac's (1996) classification scheme. Trait optimism: LOT Caregiving self-efficacy: RIS Eldercare Self-Efficacy Scale | Frequency of memory and behaviour problems significantly associated with caregiver mental health. Caregiver coping effectiveness predicts their mental health. Trait optimism and caregiving self-efficacy significantly related to caregiver mental health. Caregiver evaluation of coping effectiveness significantly related to mental health (positively), positive affect (positively) and negative affect (negatively). Coping effectiveness moderated relationship between memory and behaviour problems and caregiver negative affect. Evaluation of coping effectiveness protective factor between memory and behaviour problems and negative affect. |
|---|--|---|-------------------------------------|--|---|

| | | | | | |
|--|--|--|---------------------------------|--|---|
| | | | | | Positive affect directly influenced by trait optimism. (17) |
| Losada <i>et al.</i> , 2010 (Spain) | Investigate effects of familism and dysfunctional thoughts regarding caregiving on caregiver depression. | 334 family caregivers. Mean age: 58.6 Female: 77.8% Spouses: 36.5% Child: 56.9% Other: 6.6% | Quantitative Cross-sectional | Familism: Familism Scale Dysfunctional thoughts about caregiving: DTCQ Social support: PSQ Caregiver burden: ZBI Caregiver depression: CES-D | Dysfunctional thoughts about caregiving significantly related to caregiver depression. Familial obligations (i.e. perceived responsibility to family members) significantly associated with depression. Relationship between familial obligations and depression indirect through dysfunctional thoughts. Greater social support associated with lower depression. (19) |
| Mausbach <i>et al.</i> , 2006 (USA) | Investigate whether escape-avoidance coping acts as mediating variable between care-recipient problem behaviours | 95 spousal caregivers of Alzheimer's patients. Mean age: 72.7 Female: 72% | Quantitative Cross-sectional | Care-recipient cognitive functioning: CDR Caregiver depression: BSI Coping style: RWCC | Significant positive relationship between patient problem behaviours and caregiver depression. Escape-avoidant coping positively associated with caregiver depression. Relationship between problem |

| | | | | | |
|---|--|--|---------------------------------|--|---|
| | and caregiver depression. | | | | behaviours and caregiver depression partially mediated by level of escape avoidance. (18) |
| Mausbach <i>et al.</i> , 2008 (USA) | Investigate relationships between engagement in activities and caregiver affect. | 24 family caregivers. Mean age: 62 Female: 96% Spouses: 63% Non-spousal: 37% | Quantitative Time-series | Level of care required by care-recipient: ADL & IADL Problem behaviours: R-MBPC Caregiver affect: PANAS Activity levels: PES-AD | Total activity positively related with caregiver positive affect. Obtained pleasure positively related with caregiver positive affect. Weak inverse relationship between total activity and caregiver negative affect. Small to medium inverse relationship between obtained pleasure and caregiver negative affect. (19) |
| Mausbach <i>et al.</i> , 2009 (USA) | Investigate association between caregiver cognitive and behavioural variables and caregiver depressive symptoms. Differentiate between | 88 spousal caregivers of Alzheimer's patients. Mean Age: 73.9 Female: 73.9% | Quantitative Cross-sectional | Dementia severity: CDR Caregiver depression: CESD-10 Caregiver affect: PANAS Negative cognitions/appraisals: PMS, RWCC & RMBPC | Activity participation negatively related to depression. Caregiver helplessness, blaming self and negative appraisals all significantly and positively related to depression. Significant positive relationship |

| | | | | | |
|--|--|---|------------------------------|---|--|
| | the specific effects upon positive and negative affect. | | | Activity participation: PES-AD | between activity participation and positive affect. Helplessness, blaming self and negative appraisals significantly and positively related to negative affect. Behavioural variables associated with positive affect and cognitive variables associated with negative affect. (18) |
| O'Rourke <i>et al.</i> , 2011 (Canada) | Investigate whether marital idealisation predicts future psychological wellbeing (life satisfaction & decreased burden) of spousal caregivers. | 90 spousal caregivers of Alzheimer's patients. Mean age: 69.8 Female: 58.9% | Quantitative Longitudinal | Marital idealisation: MAS Caregiver burden: BI Life satisfaction: SLS | Older caregivers reported less burden. Higher life satisfaction significantly associated with being a male caregiver. Partner and marriage idealisation predicted lower levels of burden a year later. Burden decreased if marital idealisation increased over the course of the year. Marital idealisation predicted life satisfaction. |

| | | | | | |
|--|--|--|---------------------------------|--|--|
| | | | | | Increase in marital idealisation over course of year associated with increase in life satisfaction. If baseline marital idealisation was low, opposite pattern was demonstrated. (17) |
| Searson <i>et al.</i> , 2008 (UK) | Investigate relationship between enjoyable activities undertaken and burden in spousal caregivers. | 46 spousal caregivers of patients with mild-moderate dementia. | Quantitative Cross-sectional | Cognitive functioning: MMSE Care-recipient mood: CSDD Behavioural problems: R-MBPC Caregiver burden: GHQ-12 Enjoyable activities: PES-AD | Caregiver burden significantly related to frequency and reaction to care-recipient problem behaviours. No relationship between cognitive functioning and caregiver burden. Enjoyable activities engaged in by caregiver, patient and both together all significantly associated with lower levels of caregiver burden. (18) |

MMSE=Mini-Mental State Examination; IADL=Instrumental Activities of Daily Living Scale; ADL=Activities of Daily Living Scale; CBI=Caregiver Burden Inventory; BSI=Brief Symptom Inventory; DAD=Disability Assessment for Dementia Scale; NPI-Q=Neuropsychiatric Inventory Questionnaire; ZBI=Zarit Burden Inventory; RUD-Lite=Resource Utilization in Dementia Lite; SEDS=Subjective Experience of Distress Scale; WAI=Weinberger Adjustment Inventory; NEO-FFI=NEO Five-Factor Inventory; CES-D=Center for Epidemiologic Studies Depression Scale; CDR=Clinical Dementia Rating Scale; DSRs=Dementia Severity

Rating Scale; SF-36=Medical Outcomes Trust 36-item short-form health survey; ABS=The Affect Balance Scale; R-MBPC=Revised Memory and Behavior Problems Checklist; LOT=Life Orientation Test; DTCQ=Dysfunctional Thoughts about Caregiving Questionnaire; PSQ=Psychological Support Questionnaire; RWCC=Revised Ways of Coping Checklist; PANAS=Positive and Negative Affect Schedule; PES-AD=Pleasant Events Schedule-AD; CESD-10=Short form of Center for Epidemiologic Studies Depression Scale; PMS=Personal Mastery Scale; MAS=Marital Aggrandizement Scale; BI=The Burden Interview; SLS=Satisfaction with Life Scale; CSDD=Cornell Scale for Depression in Dementia; GHQ-12=General Health Questionnaire 12-item version.

Synthesis

Three common themes relating to variables found to be associated with psychological wellbeing were found across studies, using the data extraction form. They were: care-recipient variables; caregiver variables and family/systemic variables. These themes could be further divided into six sub-categories: care-recipient cognitive and behavioural disturbances; caregiver appraisals; caregiver coping style; familism and dysfunctional thoughts; marital idealisation; and engagement in activities. These themes were used as a framework in answering the question of what factors are associated with psychological wellbeing amongst family caregivers of IWD. The distribution of themes and sub-themes are illustrated in Figure 2. The following is a narrative synthesis of the findings across the 11 studies with respect to these themes.

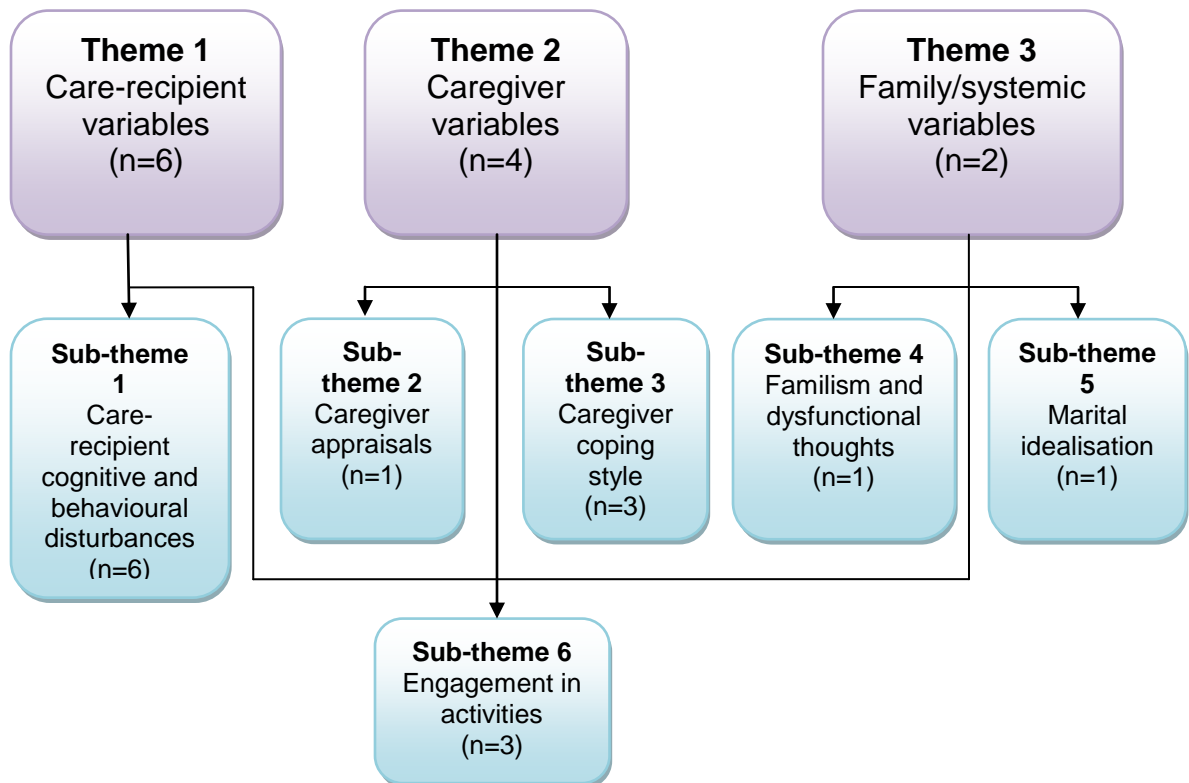


Figure 2. Themes and sub-themes identified for included studies.

(n = the number of studies which examined this variable)

Care-recipient variables

Cognitive and behavioural disturbances

Several studies suggest significant associations exist between caregiver well being and the cognitive and functional impairments experienced by dementia care-recipients, but also that certain factors might mediate these associations.

Cognitive impairment was found to be associated with family caregiver wellbeing in a number of studies. In Aguglia *et al.*'s (2004) study (see Table 1) cognitive impairment in Alzheimer's patients as measured by the Mini-Mental State Examination (MMSE) was found to be associated with higher caregiver anxiety and depression scores on the Brief Symptom Inventory (BSI) and higher levels of burden scores on the Caregiver Burden Inventory (CBI). Further support for the relationship between cognitive impairment and burden came from Bergvall *et al.* (2011) in their study of 866 caregivers of Alzheimer's patients across Sweden, Spain, UK and USA. Burden scores as measured by the Zarit Burden Inventory (ZBI) were found to significantly correlate with MMSE scores ($p < 0.05$) in all countries except for Spain.

Not all included studies found support for a relationship between degree of cognitive impairment and family caregiver wellbeing. Fisher *et al.* (2011) (for details see Table 1) found no significant correlations (all p -values > 0.05) between the main dependent variable of depression as measured by the Center for Epidemiologic Studies Depression Scale (CES-D), and care-recipient cognitive impairment measured by the Clinical Dementia Rating scale (CDR), Dementia Severity Rating Scale (DSRS) and MMSE. Searson *et al.* (2008) (see Table 1) also found no support for a specific association between care-recipient cognitive functioning as measured by the MMSE and the dependent variable of caregiver psychological wellbeing measured using the General Health Questionnaire (GHQ-12).

Functional impairments, or (instrumental) activities of daily living have also been found to be associated with family caregiver psychological wellbeing. Aguglia *et al.* (2004) reported that care-recipient behavioural functioning was associated with caregiver wellbeing. Lower Activities of Daily Living scale (ADL) and Instrumental

Activities of Daily Living scale (IADL) scores correlated with higher levels of anxiety, depression and burden (measured using CBI and BSI).

Greater support for this relationship between functional impairments and caregiver wellbeing was reported by Bergvall *et al.* (2011). Behavioural functioning as measured by the Disability Assessment for Dementia rating scale (DAD) was found to significantly correlate with ZBI scores (measuring caregiver burden) in all four of the sampled countries at ($p < 0.05$). A particularly strong relationship was found between ADLs and ZBI scores in the UK sample ($p < 0.001$). In a pooled sample of the four countries, the association between DAD scores and ZBI scores was partly mediated by informal care hours. This explained 30% of the total effect. Thus there appeared to be a role for the number of hours spent providing informal care by the family caregiver in mediating the relationship between the care-recipient's functional impairment they encounter and the burden they experience.

Several studies indicate an association between family caregiver psychological wellbeing and behavioural problems or challenging behaviour. In Fisher *et al.*'s (2011) study, the main dependent variables of depression and strain were measured using the CES-D and questions from the Caregiver Health Effects Study (Schulz & Beach, 1999). The only significant correlate of CES-D scores was Neuropsychiatric Inventory Questionnaire (NPI-Q) scores, demonstrating a significant association between family caregiver depression and care-recipient behavioural problems ($p = 0.01$). Emotional strain correlated with NPI scores ($p < 0.001$) within this study.

Depression was also measured as a dependent variable in the study conducted by Mausbach *et al.* (2006). Ninety-five spousal caregivers of Alzheimer's patients were administered the BSI and this measure was correlated with frequency of care-recipient problem behaviours including vocal repetition, incontinence and medication refusal. Depression scores on the BSI were found to significantly correlate with frequency of care-recipient problem behaviours ($p = 0.034$). Caregiver escape-avoidance coping was found to mediate this relationship (see below).

Using correlational analyses, Searson *et al.* (2008) reported a strong relationship between behavioural problem frequency and caregiver strain or burden as measured by the GHQ-12 ($p \leq 0.01$). There was an even stronger relationship between caregiver reaction scores on the Revised Memory and Behavior Problem Checklist (R-MBPC) and QHQ-12 scores, with greater levels of perceived challenge being associated with lower psychological wellbeing. This may indicate that the objective frequency of behavioural problems and the subjective difficulty experienced by family caregivers in association with these problems may interact with their psychological wellbeing to different extents.

Highlighting the importance of care-recipient behavioural disturbances when considering the psychological wellbeing of the family caregiver, this factor was found to be the strongest correlate of caregiver burden in the pooled sample of the Bergvall *et al.* (2011) study. Furthermore, unlike functional impairment, behavioural problems (measured using the NPI-Q) were found to have a strong, direct effect on caregiver burden (measured by ZBI) and not mediated by informal care hours ($p < 0.05$; effect size: 0.38). Across samples, behavioural disturbance was the strongest correlate of family caregiver burden within the UK sample ($p < 0.001$), suggesting a particularly significant role for this factor within this country.

Taking a more holistic approach, cognitive impairment, functional impairment and behavioural problems were clustered together as dementia symptoms (measured using the R-MBPC) in a study by Gottlieb and Rooney (2004). The authors administered the SF-36 and Affect Balance Scale (ABS) to 141 family caregivers of mainly Alzheimer's dementia patients and analysed these with respect to cognitive and behavioural problems as measured by the R-MBPC. They found a significant correlation between R-MBPC and SF-36 scores ($p < 0.001$), demonstrating that poor family caregiver mental health was significantly related to higher frequency of cognitive and behavioural problems. Care-recipient cognitive and behavioural problems were also associated with caregiver negative affectivity. This relationship was moderated, the authors reported, by coping effectiveness suggesting a role for coping style and self-efficacy (see below).

In summary, the studies included in this review indicate that greater frequency of, and caregiver reaction to, behavioural problems caused by dementia

are associated with poorer psychological wellbeing in family caregivers. Functional impairment was also found to be significantly associated with family caregiver psychological wellbeing, particularly in the UK. There was, however, mixed evidence as to whether degree of care-recipient cognitive impairment is associated with psychological wellbeing. As the studies by Searson *et al.* (2008) and Fisher *et al.* (2011) scored highest on quality ratings (see below), then the strength of the evidence for a link between behavioural problems and caregiver wellbeing, and the absence of a relationship between cognitive impairment and caregiver wellbeing, may be relatively greater than that of other studies.

Caregiver variables

Caregiver appraisals

Mausbach *et al.* (2009) investigated the association between caregiver cognitive and behavioural variables and caregiver depressive symptoms. These included measuring the negative appraisals made by 88 spousal caregivers of Alzheimer's patients using the Personal Mastery Scale (PMS), Revised Ways of Coping Checklist (RWCC) and R-MBPC. These measured the extent to which the caregiver believed they could influence outcomes, blamed themselves and negative reactions to dementia symptoms respectively. The researchers reported that helpless appraisals were strongly associated with caregiver depression scores on the CES-D ($p < 0.001$). Similarly, appraisals involving blaming one's self and negative reactions correlated with higher depression ($p = 0.004$) and ($p = 0.009$ respectively). The authors examined the relationship between caregiver appraisals and positive and negative affect specifically using Positive And Negative Affect Schedule (PANAS). They found that none of the appraisals were significantly correlated with positive affectivity, but they all correlated with negative affectivity. Negative reaction appraisals produced the most statistically significant correlation ($p = 0.001$) followed by helplessness appraisals ($p = 0.002$) and finally appraisals of blaming one's self ($p = 0.015$).

Caregiver coping style

The relationship between caregiver coping style and negative affect was investigated by Butt *et al.* (2002). Pruchno and Resch's (1989) coping measure was used to compare three types of emotion-focussed coping styles with self-report and informant ratings of caregiver negative affect using the Weinberger Adjustment Inventory (WAI) and NEO Five-Factor Inventor (NEO-FFI) respectively. Ninety spousal caregivers of Alzheimer's patients and 39 adult children of these participants responded. Higher levels of experienced negative affect and informant-rated neuroticism were associated with greater use of emotion-focussed coping ($p \leq 0.01$). Both measures of negative affectivity were significantly associated with less use of acceptance coping ($p\text{-values} \leq 0.05$). No relationship was found between caregiver wellbeing and instrumental coping ($p > 0.05$).

Another coping style found to be significantly associated with caregiver wellbeing is escape-avoidance. The Mausbach *et al.* (2006) study measured coping style using RWCC. They found that greater use of escape-avoidance coping strongly correlated with caregiver depressive symptoms on the BSI ($p = 0.001$). Furthermore, escape-avoidance coping was found to partially mediate the relationships between care-recipient problem behaviours and caregiver depression ($p = 0.038$).

Effectiveness of coping style used was also found to be significantly related to family caregiver wellbeing in the previously discussed Gottlieb and Rooney (2004) study. Caregiver coping effectiveness was self-reported using Gottlieb and Gignac's (1996) classification scheme. Positive framing was found to be the only style significantly associated with coping effectiveness ($p < 0.01$). In turn, greater coping effectiveness was found to reduce the relationship between care-giving demands and negative affect ($p < 0.04$) thus providing a buffering effect.

In summary, the studies reviewed indicate that acceptance coping, positive framing and greater coping effectiveness are associated with better family caregiver psychological wellbeing whilst emotion-focussed and escape-avoidance coping strategies are associated with poorer caregiver wellbeing outcomes.

Family/Systemic variables

Familism and dysfunctional thoughts

Losada *et al.* (2010) investigated the effects of familism (factors relating to the culture within the individual's family) and dysfunctional thoughts regarding caregiving on caregiver depression amongst 334 family caregivers of IWD in Spain. Caregivers completed the Familism Scale to measure familial obligations, perceived support from the family and family as referents. Social support was measured using the Psychological Support Questionnaire (PSQ). Participants also completed the Dysfunctional Thoughts about Caregiving Questionnaire (DTCQ) to measure dysfunctional thoughts which could prevent adaptation to the care-giving task. Family caregiver wellbeing was measured using the ZBI to measure burden and the CES-D to measure depression. Dysfunctional thoughts were significantly associated with caregiver depression ($p < 0.01$). A significant relationship was found between familial obligations and depression ($p < 0.01$) but neither perceived support from family or viewing family as referents was associated with depression ($p > 0.05$). Only perceived social support significantly correlated (inversely) with burden scores ($p < 0.05$). An inverse relationship was also found between perceived social support and caregiver depression ($p < 0.05$). Using path analysis, the relationship between familial obligations and caregiver depression was found to be indirect through dysfunctional thoughts and so perceived responsibility to the family may only predict depression if it is also associated with negative thinking.

Marital idealisation

In a Canadian study, O'Rourke *et al.* (2011) investigated how marital idealisation predicts caregiver wellbeing. In the only longitudinal study included in this review, 90 spousal caregivers of Alzheimer's patients were given the Marital Aggrandizement Scale (MAS) to measure both idealisation of participants' partners and also their marriage. Caregiver burden and caregiver life satisfaction were measured using the Burden Inventory (BI) and Satisfaction with Life Scale (SLS) respectively. Correlational analysis revealed that greater idealisation of one's partner and marriage at baseline was associated with lower levels of burden one

year later ($p < 0.05$). Furthermore, the authors reported that increase in marital idealisation over the year predicted a decrease in burden scores relative to baseline ($p < 0.05$). Greater marital idealisation also predicted higher life satisfaction ($p < 0.01$). Increase in marital idealisation predicted an increase in life satisfaction over a one-year period ($p < 0.05$). In separate analyses, caregiver age was found to be inversely proportionate to burden ($p < 0.01$) and males produced significantly higher life satisfaction scores than females ($p < 0.01$).

Engagement in activities

Engagement in activities was examined with respect to activities undertaken by care-recipient, caregiver and both together as a family (Mausbach *et al.*, 2008; Searson *et al.*, 2008; Mausbach *et al.*, 2009).

Mausbach *et al.* (2008) investigated the relationship between engagement in activities and caregiver affect in a study of 24 dementia family caregivers in North America. The main outcome of positive and negative affect was measured using PANAS and these scores were correlated with caregiver engagement in activities using the Pleasant Events Schedule-AD (PES-AD). Total activity undertaken by participants was associated with positive affect with a medium to large effect found ($r = 0.42$). A positive relationship was also found between obtained pleasure from activities undertaken and positive affect ($r = 0.42$) with 18 participants producing a significant correlation ($p < 0.05$). A small inverse relationship was found between total caregiver activity participation and negative affect ($r = -0.12$), this was not significant. A small to medium effect was found in an inverse relationship between obtained pleasure and negative affect ($r = -0.17$).

Caregiver participation in pleasurable activities measured using the PES-AD was also found to have a significant inverse correlation with their depression scores on the CES-D ($p = 0.041$) by Mausbach *et al.* (2009). Activity participation was also found to positively correlate with positive affect ($p = 0.001$), but no relationship was found between activity participation and negative affect ($p > 0.05$).

In Searson *et al.*'s (2008) study into the relationship between enjoyable activities undertaken and caregiver wellbeing, there was a significant inverse relationship between caregiver burden scores on the GHQ-12 and enjoyable

activities undertaken by: caregivers ($p=0.042$); care-recipients ($p=0.033$); and by caregiver and care-recipient together ($p=0.012$). A multiple regression analysis revealed that pleasurable activities undertaken together was the only significant predictor of caregiver burden scores ($p=0.028$) which explained 14% of the total variance.

Consequently, in addition to pleasurable activities engaged in by the family caregiver alone, pleasurable activities engaged in with the care-recipient as well was reported as having a strong buffering effect toward family caregiver psychological wellbeing. This highlights a systemic component as well as a caregiver behavioural factor which may be implicated in the caregiving process and wellbeing outcomes.

Methodological quality

The bespoke quality checklist was applied to all studies included in the review and total quality scores are presented in Table 1. Inter-rater agreement with an anonymous reviewer was 81.8%. Papers scoring high were Mausbach *et al.* (2008) and Losada *et al.* (2010); both achieving a total score of 19/20 for quality. Three further studies scored 18/20 (Searson *et al.*, 2008; Mausbach *et al.*, 2009; Fisher *et al.*, 2011).

The majority of studies provided a clear rationale, design and exposition of the results. The study by Aguglia *et al.* (2004) however scored very low on quality (8/20) and did not report p -values. It scored lower than the other ten papers on items related to participant characteristics and measurements. The limitations this places on what this study can contribute to the review aims will be discussed in the *Discussion* section. The second lowest quality score was obtained by Butt *et al.* (2002) which was rated at 16/20. This meant that most papers received reasonably high overall quality scores.

Many (8) of the studies lost a quality point associated with participant characteristics as they lacked descriptive characteristics of care-recipients. Three studies did report these figures (Mausbach *et al.*, 2008; Searson *et al.*, 2008; Fisher *et al.*, 2011). The implications this has on the generalisability of research findings will be discussed later.

Studies scoring high on criteria associated with participants, sampling bias and generalisability should be identified as these studies may be more representative in their findings. Two studies met the criteria for all five items of the quality checklist relating to these factors (Mausbach *et al.*, 2008; Fisher *et al.*, 2011).

Also of particular interest are those studies scoring high on quality assessments of measurements taken. This is because they would seem to be the most relevant in clarifying factors associated with family caregiver wellbeing. Six of the eleven studies reviewed scored 3/3 on items related to measurements (Gottlieb & Rooney, 2004; Mausbach *et al.*, 2006; Searson *et al.*, 2008; Mausbach *et al.*, 2009; Fisher *et al.*, 2011; O'Rourke *et al.*, 2011).

Discussion

Family caregiver psychological wellbeing

The present review aimed to expand upon the limited focus on BPSD and burden by Black and Almeida (2004) and examine the numerous consequences of dementia that may be associated with family caregiver psychological wellbeing within the current context of the growing population of family members providing care for an IWD (McDaid, 2001; Boyle 2010). Of particular interest were the constructs of psychological wellbeing involved in and affected by caring for a family member with dementia, and what are the particular consequences of dementia associated with each of these.

Six constructs related to caregiver psychological wellbeing were examined across the eleven studies included in the review. These were burden, depression, affectivity, anxiety, life satisfaction and general mental health. This range of outcomes may relate to a lack of construct validity of 'burden' and indicate a need for researchers to look beyond this as a construct and investigate valid variables of psychological wellbeing which are clinically applicable (see Black and Almeida, 2004). This justifies the analysis of psychological wellbeing as a broader concept within this review, and demonstrates the clinical relevance and subsequent importance of not limiting research to one dimension such as burden or

depression. Differing and sometimes complex relationships were discovered between differing domains of family caregiver wellbeing and numerous experiences when caring for an IWD. One example of this is Mausbach *et al.*'s (2009) paper which presented evidence that negative affectivity is associated with cognitive caregiver variables, and positive affectivity is associated with behavioural variables. This finding is significant as it suggests there may be mutually exclusive relationships present between factors associated with family caregiver psychological wellbeing. It also identifies and supports the potential role of positive psychology briefly discussed in the introduction with respect to Pinquart and Sörensen (2003). These are areas which would be important to investigate further in order to understand potential detriments and buffers to the wellbeing of those who care for a family member with dementia. This could help to inform the provision of support and services for this growing population.

The extracted themes and sub-themes (see above) indicate some empirical support for Pearlin *et al.*'s (1990) stress-process model of caregiving. Background and contextual factors found within the present review were represented by marital idealisation, whereby marital idealisation predicted greater family caregiver life satisfaction and less burden (O'Rourke *et al.*, 2011). Primary stressors linked to the care-recipient revolved mainly around the cognitive and behavioural symptoms of dementia, with greater and more frequent dysfunction in these areas being associated with higher levels of caregiver anxiety, depression and burden (Gottlieb & Rooney, 2004; Mausbach *et al.*, 2006; Searson *et al.*, 2008; Bergval *et al.*, 2011; Fisher *et al.*, 2011). There was some evidence that 'secondary' stressors linked to the system around the caregiver were also associated with wellbeing. Familial obligations of duty-of-care to relatives were associated with greater levels of depression in the family caregiver (Losada *et al.*, 2010). These findings highlight the importance of providing mental health support for spousal and family caregivers through statutory and voluntary services. The lack of included papers reporting on changes in identity could reflect a lack of this in the literature. Equally this could represent a limitation of the present review as psychological wellbeing was operationalised in hedonic as opposed to eudaimonic (relating to meaning and self-realisation) terms. The inclusion of studies that have focused on meaning-

related positive aspects of caregiving might have created a review more sensitive to issues surrounding identity and concepts of self (Ryan & Deci, 2001).

Across the studies there was some evidence of mediating effects between the direct consequences of dementia and family caregiver psychological wellbeing. Support was found for caregiver coping style and self-efficacy mediating the relationship between dementia severity and family caregiver psychological wellbeing. Higher levels of coping effectiveness and lesser use of escape-avoidance coping were found to serve as a buffering factor against caregiver distress (Gottlieb & Rooney, 2004; Mausbach *et al.*, 2006). This provides partial support that Folkman and Lazarus' (1980, 1990) proposed role of caregiver coping in the caregiving process (i.e. effective coping style and a greater sense of mastery buffers caregiver wellbeing) may apply to family caregivers of IWD and is also consistent with Pearlin *et al.*'s (1990) stress-process model. It could be of future interest to investigate if Corcoran's (2011) coping styles could be validated as a part of this process. An additional mediating role of hours spent providing care was found within the relationship between behavioural disturbance and family caregiver burden (Bergval *et al.*, 2011). Contrary to Pearlin *et al.*'s (1990) model, Losada *et al.* (2010) report a direct relationship was found between social support and burden with greater perceived social support associated with lower levels of burden. A direct relationship was also found between caregiver appraisals and negative affect (Mausbach *et al.*, 2009). Therefore there appears to be some evidence for a number of primary and secondary factors relating to care-recipient, caregiver and the system which might work individually and/or interact with other factors in association with family/spousal caregiver psychological wellbeing.

An important consideration when relating the findings of the reviewed literature to psychological theory is that the studies were non-experimental in design and primarily used correlational analyses. This means that causality cannot be assumed and so use of the term 'predictive' such as that employed by O'Rourke *et al.* (2011) may be misleading. In some relationships, such as that between coping style and depression, the psychological wellbeing of the caregiver may be the cause of the coping style used. Family caregivers with greater negative affective states may be more likely to use emotion-focussed coping and less

acceptance-coping (Butt *et al.*, 2002) rather than these coping styles influencing their wellbeing. Future research therefore should be cautious as to what conclusions are drawn regarding cause and effect relationships in this field and should aim to address potential interpretation bias. Employment of longitudinal designs may help to establish which variables are stable and have causal effects on caregiver wellbeing over time.

Implications of methodological quality

As stated in the *Results* section, greater weighting should be placed on studies achieving higher scores on methodological quality, particularly those indicative of validity in measurement and generalisability of findings. As the study by Aguglia *et al.* (2004) achieved a total quality score of 8/20, with 1/5 on items related to participant characteristics, sampling bias and generalisability, and 1/3 on items related to measurements, the generalisability and validity of apparent evidence that behavioural disturbance is associated with higher levels of anxiety, depression and burden is questionable and this study cannot be used in order to draw firm conclusions related to the review questions.

Six studies scored 3/3 on items related to the measures used and so can be considered to be valid measures of psychological wellbeing in family caregivers of IWD (Gottlieb & Rooney, 2004; Mausbach *et al.*, 2006; Searson *et al.*, 2008; Mausbach *et al.*, 2009; Fisher *et al.*, 2011; O'Rourke *et al.*, 2011). This can be seen as supportive of the discussion above indicating that caregiver coping and appraisals, care-recipient behavioural disturbances, and marital idealisation are particularly relevant in answering the review question of what factors are associated with the psychological wellbeing of family caregivers of IWD.

The studies by Mausbach *et al.* (2008) and Fisher *et al.* (2011) scored 5/5 on items measuring participant characteristics, sampling bias and generalisability on the quality checklist. This means that the relationships found between caregivers' engagement in pleasurable activity and positive affect, and care-recipient behavioural disturbance and caregiver depression are likely to be the most representative of actual patterns within the population of dementia caregivers.

Limitations of the review

The small sample of eleven studies included in the review makes it difficult to establish definitive answers to the review questions. This may be an indication that either the search criteria were too specific, the search strategy was not sensitive enough, or alternatively, that the extant literature is too limited. Only one longitudinal study was included in the review (O'Rourke *et al.*, 2011); this type of study design could be instrumental in providing representative information regarding potential change in family caregiver psychological wellbeing over time. This could be of clinical relevance due to the progressive nature of dementia.

One exclusion criterion which restricted studies included was the exclusion of care-recipients under the age of 65. This was done as it was unknown whether young onset dementia could be linked to wellbeing differently and consequently confound results. It could be of significant value to investigate any differences in caregiver responses to dementia in older adults compared to working-age adults in order to justify inclusion criteria for future empirical research and reviews. This could also have clinical implications in terms of helping to establish whether caregivers of these different age groups require distinct support from mental health and community services.

The use of a qualitative narrative to analyse the results of this review over a meta-analysis method may limit the reliability of the findings. A qualitative narrative was used as significant translation of data would have to occur given the range of outcome measures used for measuring the variable of psychological wellbeing. If one dimension of psychological wellbeing such as depression or burden were investigated, then a meta-analytic approach may be more appropriate in the future. This would also require adaptation to the search strategy in order to be more inclusive.

There are benefits to retaining the broad concept of psychological wellbeing; it allowed for the identification of separate relationships between variables which may be more representative of the processes present for family caregivers of IWD. Future reviewers should give particular consideration to the balance of specificity with representativeness.

A future review of the relationship between caregiver wellbeing and caring behaviours would complement the present review in order to provide a more complete picture of the caregiving process for a family caregiver of an IWD.

Conclusion

This paper aimed to systematically review the literature in order to discover what factors are associated with the psychological wellbeing of family caregivers of IWD within the current context. Findings provided partial support for Pearlin *et al.*'s (1990) model. Multiple consequences of dementia were associated with caregiver wellbeing, with evidence found for mutually exclusive relationships such as those found within the tripartite model of depression: caregiver cognitive factors were associated with negative affect and caregiver behavioural factors with positive affectivity. There was also mixed support for interactions between factors consistent with Folkman and Lazarus' (1980, 1990) transactional model of stress. The most robust studies pointed towards a strong role for caregiver coping and appraisals, care-recipient behavioural disturbances, marital idealisation and caregiver engagement in pleasurable activities in the caregiving process. As studies used correlational analyses, causation cannot be determined. Further research into the relationships between caregiver processes (including coping, appraisals and familial factors) and their caregiving/helping behaviours would help develop the clinical implications of these findings. It is however clear that it is important to providing emotional support to spousal and family caregivers of IWD throughout their caregiving task.

References

- Aguglia, E., Onor, M.L., Trevisiol, M., Negro, C., Saina, M. & Maso, E. (2004). Stress in the caregivers of Alzheimer's patients: an experimental investigation in Italy. *American Journal of Alzheimer's Disease and Other Dementias*, 19(4), 248-252.
- Ballard, C., Lowery, K., Powell, I., O'Brien, J. & James, I. (2000). Impact of behavioral and psychological symptoms of dementia on caregivers. *International Psychogeriatrics*, 12(1), 93-105.
- Bergvall, N., Brinck, P., Gustavsson, A., Wimo, A., Winblad, B. & Jönsson, L. (2011). Relative importance of patient disease indicators on informal care and caregiver burden in Alzheimer's disease. *International Psychogeriatrics*, 23(1), 71-85.
- Black, W. & Almeida, O.P. (2004). A systematic review of the association between the behavioral and psychological symptoms of dementia and burden of care. *International Psychogeriatrics*, 16(3), 295-315.
- Boerner, K., Schulz, R. & Horowitz, A. (2004). Positive aspects of caregiving and adaptation to bereavement. *Psychology and Aging*, 19(4), 668-675.
- Boyle, G. (2010). Social policy for people living with dementia in England: promoting human rights? *Health and Social Care in the Community*, 18(5), 511-519.
- Butt, Z.A., Strauss, M.E., Smyth, K.A. & Rose-Rego, S.K. (2002). Negative affectivity and emotion-focussed coping in spouse caregivers of persons with Alzheimer's disease. *The Journal of Applied Gerontology*, 21(4), 471-483.

- Chen, C.P. (2004). Transcultural expression of subcortical vascular disease. *Journal of the Neurological Sciences*, 226, 45-47.
- Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry*, 17, 184–188.
- Corcoran, M. (2004). Caregiving styles and strategies. In K. Dokar (Ed.), *Living with grief: Alzheimer's disease* (pp. 197-212). Washington, DC: Hospice Foundation of America.
- Corcoran, M.A. (2011). Caregiving styles: a cognitive and behavioural typology associated with dementia family caregiving. *The Gerontologist*, 51(4), 463-472.
- Di Mattei, V.E., Prunas, A., Novella, L., Marcone, A., Cappa, S.F. & Sarno, L. (2008). The burden of distress in caregivers of elderly demented patients and its relationship with coping strategies. *Neurological Sciences*, 29, 383-389.
- Downs, S.H. & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomized and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health* 52(6), 377-384.
- Finkel, S. I., Costa, E., & Silva, J. (1996). Behavioural and psychological signs and symptoms in dementia – a consensus statement on current knowledge and implications for research and treatment. *International Psychogeriatrics*, 8, 497-500.
- Fisher, G.G., Franks, M.M., Plassman, B.L., Brown, S.L., Potter, G.G., Llewellyn, D., Rogers, M.A.M. & Langa, K.M. (2011). Caring for individuals with

dementia and cognitive impairment, not dementia, findings from the aging, demographics, and memory study. *Journal of the American Geriatrics Society*, 59(3), 488-494.

Folkman, S. & Lazarus, R.S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health & Social Behavior*, 21, 219-239.

Folkman, S. & Lazarus, R.S. (1990). Coping and emotion. In N.L.L.B. Stein (Ed.), *Psychological and biological approaches to emotion* (pp. 313-332). Hillsdale, NJ: Lawrence Erlbaum.

Ganguli, M., Dodge, H.H., Shen, C., Pandav, R.S., & DeKosky, S.T. (2005). Alzheimer Disease and Mortality: A 15-Year Epidemiological Study. *Archives of Neurology*, 62, 779-784.

Gottlieb, B.H. & Gignac, M.A. (1996). Content and domain specificity of coping among family caregivers of persons with dementia. *Journal of Aging Studies*, 10(2), 137-155.

Gottlieb, B.H. & Rooney, J.A. (2004). Coping effectiveness: determinants and relevance to the mental health and affect of family caregivers of persons with dementia. *Aging and Mental Health*, 8(4), 364-373.

Harden, A., Garcia, J., Oliver, S., Rees, R., Shepherd, J., Brunton, G., & Oakley, A. (2004). Applying systematic review methods to studies of people's views: an example from public health research. *Journal of Epidemiology and Community Health* 58, 794-800.

Helzner, E.P., Scarmeas, N., Cosentino, S., Tang, M.X., Schupf, N., & Stern, Y. (2008). Survival in Alzheimer disease: A multiethnic, population-based study of incident cases. *Neurology*, 71(19), 1489-1495.

- Keady, J., Harris, P. & Wilkinson, H. (2002). *Dementia: The International Journal of Social Research and Practice*. London: Sage Publications.
- Kinoshita, T. & Hanabusa, H. (2010). Issues facing home-based medical support services. *Psychogeriatrics: The Official Journal Of The Japanese Psychogeriatric Society*, 10(2), 90-94.
- Knapp, M., Prince, M., Albanese, E., Banerjee, S., Dhanasiri, S., Fernandez, J. L., Ferri, C., McCrone, P. & Stewart, R. (2007). *Dementia UK*. London: Alzheimer's Society.
- Knussen, C., Tolson, D., Brogan, C.A., Swan, I.R.C., Stott, D.J. & Sullivan, F. (2008). Family caregivers of older relatives: ways of coping and change in distress. *Psychology, Health and Medicine*, 13, 274-290.
- Kramer, B.J. (1997). Gain in the caregiving experience: Where are we? What next? *The Gerontologist*, 37(2), 218-232.
- Langa, K.M., Chernew, M.E., Kabeto, M.U., Herzog, A.R., Ofstedal, M.B., Willis, R.J., Wallace, R.B., Mucha, L.M., Straus, W.L. & Fendrick, A.M. (2001). National estimates of the quantity and cost of informal caregiving for the elderly with dementia. *Journal of General Internal Medicine*, 16(11), 770-778.
- Larson, E.B., Shadlen, M. F., Wang, L., McCormick, W.C., Bowen, J.D , Teri, L., & Kukull, W.A. (2004). Survival after Initial Diagnosis of Alzheimer Disease. *Annals of Internal Medicine*, 140(7), 501-509.
- Losada, A., Márquez-González, M., Knight, B.G., Yanguas, J., Sayegh, P. & Romero-Moreno, R. (2010). Psychosocial factors and caregivers' distress: effects of familism and dysfunctional thoughts. *Aging and Mental Health*, 14(2), 193-202.

- Mausbach, B.T., Aschbacher, K., Patterson, T.L., Ancoli-Israel, S., van Känel, R., Mills, P.J., Dimsdale, J.E. & Grant, I. (2006). Avoidant coping partially mediates the relationship between patient problem behaviours and depressive symptoms in spousal Alzheimer caregivers. *American Journal of Geriatric Psychiatry*, 14(4), 299-306.
- Mausbach, B.T., Coon, D.W., Patterson, T.L. & Grant, I. (2008). Engagement in activities is associated with affective arousal in Alzheimer's caregivers: a preliminary examination of the temporal relations between activity and affect. *Behavior Therapy*, 39(4), 366-374.
- Mausbach, B.T., Roepke, S.K., Depp, C.A., Patterson, T.L. & Grant, I. (2009). Specificity of cognitive and behavioral variables to positive and negative affect. *Behaviour Research and Therapy*, 47, 608-615.
- McDaid, D. (2001). Estimating the costs of informal care for people with Alzheimer's disease: methodological and practical challenges. *International Journal of Geriatric Psychiatry*, 16, 400-405.
- Nolan, M., Grant, G. & Keady, J. (1996). *Understanding Family Care: A Multidimensional model of Caring and Coping*. Open University Press: Buckingham and Philadelphia.
- O'Rourke, N., Claxton, A., Kupferschmidt, A.L., Smith, J.Z & Beattie, B.L. (2011). Marital idealization as an enduring buffer to distress among spouses of persons with Alzheimer disease. *Journal of Social and Personal Relationships*, 28(1), 117-133.
- Park, M. (2002). Korean family caregivers' perceptions of care in dementia care units. *Journal of the Korean Academy of Nursing*, 32(7), 967-976.

- Pearlin, L.I., Mullan, J.T., Semple, S.J. & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30(5), 583-594.
- Pinquart, M. & Sörensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *Journals of Gerontology. Series B: Psychological Sciences and Social Sciences*, 58,112-128.
- Pruchno, R.A. & Resch, N.L. (1989). Mental health of caregiving spouses: coping as a mediator, moderator or main effect? *Psychology & Aging*, 4, 454-463.
- Ryan, R.M. & Deci, E.L. (2001). On happiness and human potentials: a review of research on hedonic and eudaimonic well-being. *Annual Review of Psychology*, 52, 141-166.
- Searson, R., Hendry, A.M., Ramachandran, R., Burns, A. & Purandare, N. (2008). Activities enjoyed by patients with dementia together with their spouses and psychological morbidity in carers. *Aging and Mental Health*, 12(2), 276-282.
- Schulz, R. & Beach, S.R. (1999). Caregiving as a risk factor for mortality. *Journal of the American Medical Association*, 282, 2215-2219.
- Schulz, R., O'Brien, A.T., Bookwala, J. & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates and causes. *Gerontologist*, 35, 771-791.
- Vandenbroucke, J.P., von Elm, E., Altman, D.G., Gotzsche, P.C., Mulrow, C.D., Pocock, S.J., Poole, C., Schlesselman J.J., & Egger, M.; STROBE Initiative. (2007). Strengthening the reporting of observation studies in epidemiology (STROBE): Explanation and elaboration. *Epidemiology* 18(6), 805-835.

Vellone, E., Piras, G., Talucci, C. & Cohen, M.Z. (2008). Quality of life for caregivers of people with Alzheimer's disease. *Journal of Advanced Nursing*, 61(2), 222-231.

World Health Organization (1992) *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*. Geneva: WHO.

Part Two

Empirical Paper

Family Caregiver Responses to Challenging Behaviour in Dementia

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Family Caregiver Responses to Challenging Behaviour in Dementia

ABSTRACT

Title of manuscript: Family caregiver responses to challenging behaviour in dementia

Name of journal: Aging & Mental Health

Objectives: This study aimed to test Weiner's (1985) attributional model of helping behaviour amongst family caregivers of individuals with a diagnosis of dementia (IWD). This model suggests a link between attributions of controllability and stability, emotional responses of anger and sympathy, and willingness to help.

Method: Fifty-two spousal and family caregivers of IWD completed written self-report measures including the Revised Memory and Behavior Problem Checklist and took part in a semi-structured interview which the Leeds Attributional Coding System was then applied to. Correlational and regression analyses were employed to test the suitability of a mediator model of willingness to help, purporting that emotional response mediating a relationship between attributions and propensity to help.

Results: The results did not support the application of Weiner's (1985) attributional model of helping behaviour amongst family caregivers of IWD. No significant relationships were found between attributions and willingness to help. However, findings from previous work suggesting important roles for optimism and sympathy in the help-giving process were replicated.

Conclusion: It was not possible to draw firm conclusions from the presented findings. It is suggested that alternative models such as the stress-process model should be investigated and methodological issues should be addressed in future research. Implications for future research and within the clinical context are discussed.

Key Words: family; caregiver; dementia; attribution; behaviour.

Introduction

Dementia and care-giving

Dementia is a syndrome characterised by progressive decline of memory, judgement, thinking, emotional control, social behaviour and motivation as a result of gradual brain cell death (WHO, 1992). The Alzheimer's Research Trust (ART; 2010) revealed that over 820,000 people across the United Kingdom have dementia, with Knapp *et al.* (2007) predicting a rise to 1,735,087 by 2051.

Following a diagnosis of dementia an individual can expect, on average, to live a further 3-9 years (Ganguli *et al.*, 2005; Helzner *et al.*, 2008; Larson *et al.*, 2004) during which time they will invariably need someone to support them.

Approximately 63% of Individuals with Dementia (IWD) live at home (ART, 2010) and there are estimated to be 600,000 people in the UK acting as unpaid primary carers for IWD (Alzheimer's Society, 2007); usually a spouse or a close family member. Projected increases in the prevalence of dementia together with increased emphasis on home-based support and availability of medications for dementia are likely to increase the prevalence of older IWD living and being cared for at home by such informal caregivers (Boyle, 2010).

Challenging behaviour in dementia

Family caregivers of IWD may encounter one or more Behavioural and Psychological Symptoms of Dementia (BPSD) which can include depression, anxiety, delusions, wandering, excessive verbalisation, agitation and sexual disinhibition amongst other symptoms (Finkel, Costa, & Silva, 1996). BPSD are often perceived and experienced as challenging behaviour (CB) by caregivers. In dementia, CB has been described as behaviour which is perceived as "disruptive, aggressive or difficult" (Cunningham, 2006, p.42).

Caregiver beliefs regarding CB are likely to be associated with their responses to it. In particular, formal caregivers' perceptions of dementia-related CB in the form of attributions (beliefs about the cause of a person's action or problem) may influence the way these behaviours are managed (Fopma-Loy & Austin, 1997). However, the beliefs, responses and management strategies unique to

family caregivers who encounter CB when caring for an IWD at home remain relatively unexamined in the literature, despite the important role identified for these persons in recent UK healthcare policy initiatives (NICE, 2006; DoH, 2009).

Challenging behaviour, attributions and helping behaviour

Care provision is the outcome of interacting cognitive, behavioural, emotional factors and systemic factors (Corcoran, 2011). As care-giving can be conceptualised as a type of helping behaviour, it may be understood in terms of Weiner's (1985) cognitive-emotional model of attributional theory (AT) applicable to helping behaviour. This is summarised in Figure 1. It posits that individuals will be more willing to engage in helping behaviour if the cause of the observed behaviour is perceived as having: 1) Low controllability, which elicits sympathy/pity as it is interpreted that the behaviour could not have been helped by the individual; and/or 2) High stability, which further increases sympathy/pity as the individual is judged as not being able to help themselves in the future. According to this model, people are less inclined to help if a behaviour is perceived as having high controllability, which elicits anger as the event/behaviour is perceived as being within the individual's volition. Whilst stable attributions are proposed to influence sympathy, there is no explicit reference in Weiner's model to how attributions of low stability would affect propensity to help.

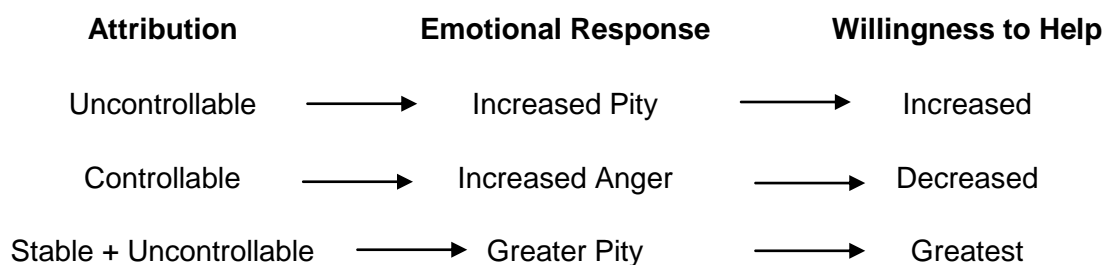


Figure 1. Weiner's (1985) Attributional theory of helping behaviour

Investigations into the links between attributions, emotional responses and helping behaviours in clinical settings have been inconsistent in their findings. In a literature review of the Learning Disability (LD) field, Wilner and Smith (2008) found

inconsistent evidence that controllability and stability affected paid care staff's propensity to help individuals with a LD whose behaviour was challenging. Their review highlighted issues regarding the operationalisation of the dependent variable of willingness to help as existing studies have tended to measure expansion of effort without a focus on whether this behaviour helped prevent the recurrence of a CB.

Similarly, there has been mixed support for Weiner's (1985) model in relation to dementia. Tarrier *et al.* (2002) found that caregivers with high Expressed Emotion (EE), which involves hostility/criticism and low warmth, made more personal and controllable attributions about challenging behaviours; warm caregivers made less personal and more uncontrollable attributions and over-involved caregivers made attributions external to the person cared for and internal to themselves. This indicated an association between internal and controllable attributions and EE and strain in the caregiver. However this study failed to specifically examine links between attributions, emotional responses and propensity to provide help according to Weiner's (1985) model.

Todd and Watts (2005) investigated whether Weiner's cognitive-emotional model could be applied to understanding the helping behaviours of professional staff working with IWD who were perceived as exhibiting CB. In an investigation using the recall of a recent personal encounter of CB by 25 nurses and 25 clinical psychologists, they found that optimism and sympathy led to willingness to help whereas burnout was associated with less willingness to help, low optimism and negative emotional affect. Sympathy and optimism have also been found to be significant predictors of helping behaviour in other populations, specifically staff working in a medium-secure mental health institution and carers of children in a residential home (Sharrock *et al.*, 1990; McGuiness & Dagnan, 2001 respectively). The actual attributions made by staff in the Todd and Watts (2005) study did not have a consistent effect on emotional response or reported behaviour, something also evident when vignettes have been used to explore caregivers of IWD's responses to CB (Fopma-Loy & Austin, 1993, 1997), however this may have been due to the use of vignettes greatly reducing ecological validity. Fopma-Loy and Austin (1997), however, did find some evidence of a relationship between

attributions, positive expectations and help-giving behaviour. Taken together, these studies suggest a potential link between attributions and willingness to help and may also reveal a role for optimism. Furthermore, Dagnan, Grant and McDonnell (2004) found emotional responses and subsequent behaviours in response to dementia-related CB to be related to attributions of controllability. However, the roles of other types of attributions were not investigated and propensity to help as an outcome went unreported in their study.

Optimism

Carver, Spencer, and Scheier (1998) describe how high trait optimism predicts the expectation of a positive outcome independent of external challenges. As already indicated, optimism may influence the cognitive, emotional and behavioural responses of family caregivers of IWD; if they have high optimism then they may perceive a behaviour as less challenging and respond more positively. However, beliefs regarding the outcome of caring for IWD are likely to be part of a process involving additional factors to trait optimism. Specific outcome expectancies may also be influenced by the context/situation and caregiver previous experiences (Armor & Taylor, 1998; Bandura, 1982). Given this and the previously discussed findings (Sharrock *et al.*, 1990; Fopma-Loy & Austin, 1997; McGuinness & Dagnan, 2001; Todd & Watts, 2005), it is important to consider self-efficacy regarding caregiving performance specific to the CB investigated whilst measuring attributions and caregiver responses.

Rationale for the current study

There is a large gap in the empirical literature in relation to whether Weiner's (1985) cognitive-emotional model of helping behaviour is applicable to the help-giving behaviour of family caregivers of IWD. Although the findings of Tarrier *et al* (2002) suggest important links between attributions, emotional responses and carer strain, the way that specific attributions and emotions might influence family caregivers' experiences of and reactions to BPSD in dementia is still relatively unclear. As such, the key aims of this study were to investigate the applicability of Weiner's (1985) model by determining the extent to which perceived levels of

challenge and propensity to provide help amongst informal family caregivers of IWD are influenced by attributions and associated emotional responses.

This study aimed to overcome previous methodological issues associated with the study of attributions and responses to CB by limiting measured attributions to the dimensions of controllability and stability and the mediating variables to sympathy and anger, as these are the specific cognitive and emotional responses in Weiner's (1985) original model that are proposed to predict help-giving behaviour. Optimism was also included as recent research suggests there is an important role for this construct (Sharrock *et al.*, 1990; Fopma-Loy & Austin, 1997; McGuinness & Dagnan, 2001; Gottlieb & Rooney, 2004; Todd & Watts, 2005). Furthermore, we aimed to increase the validity of the measurement of mediating variables and helping behaviour by using participants' own language to define terms synonymous with sympathy and anger, by using multiple measurements of willingness to help and also by using recent real-life accounts of experience with CB, rather than employing vignettes.

Research questions

1. What beliefs do family caregivers hold about the causes of perceived challenging behaviour?
2. Do attributions (of controllability and stability) predict willingness to help amongst family caregivers supporting IWD?
3. Do attributions (of controllability and stability) predict perceived levels of challenge of BPSD in family caregivers?
4. To what extent do emotional response and/or optimism mediate any relationships between attributions and help-giving behaviours?
5. To what extent do emotional responses and/or optimism mediate any relationship between attributions and perceived level of challenge?

Hypotheses

Primary hypothesis

Emotional responses of sympathy and anger will mediate the relationship between attributions and helping behaviours.

Secondary hypotheses

1. Attributions of a behaviour as uncontrollable and stable will predict an increased propensity to help.
2. Attributions of a behaviour as controllable and unstable will predict a decreased propensity to help.
3. Optimism will mediate the relationship between attributions and propensity to help.
4. Attributions of a behaviour as controllable will predict an increased perceived level of challenge.
5. Emotional response will mediate the relationship between attributions and perceived level of challenge.
6. Optimism will mediate the relationship between attributions and perceived level of challenge.

Method

Design

A cross-sectional design was used where quantitative data was collected through the use of self-report measures and a semi-structured interview. Correlational and regression analyses were used to test for mediating relationships according to the mediator model outlined by Baron and Kenny (1986). The dependent variables in this study were propensity to help and perceived level of challenge. The independent variables were attributions of controllability (controllable/uncontrollable) and stability (stable/unstable). The mediating variables were emotional response (sympathy and anger) and optimism.

Participants

This study was given ethical approval by an NHS Research Ethics Committee on 4th May 2011 (Appendix E) and recruitment was authorised by the appropriate NHS

Research and Development departments. The target number of participants in order to achieve 80% power for the study based on Fritz and MacKinnon (2007) was 59. Fifty-two family caregivers of older adults with dementia were recruited through NHS memory and mental health services, Alzheimer's Society events and council services in the north of England. Additionally, participants were identified and recruited through an ongoing large-scale research project into family caregivers in the north of England. Inclusion criteria included spouses or family members providing instrumental care (for example personal care, shopping, cooking and finances) and/or emotional support for an individual over the age of 65 with a diagnosis of dementia. Participants had to be aware of the care-recipient's diagnosis and either live with them or be the main family caregiver, providing care on at least one occasion per week for at least two months prior to their participation in the study. Participants were excluded if they were a professional caregiver, if the care-recipient had a diagnosis of a reversible dementia, or if English was not their primary language. For demographic information of participants, see Results.

Measures

Demographic information

Data was gathered regarding participants' age, sex, relationship to the care-recipient, time since becoming a caregiver, hours spent providing care per week and the types of care provided by the caregiver. Information was also sought regarding the age, sex, diagnosis and time since diagnosis of the care-recipient.

Attributions

Attributions were extracted from a 10-minute face-to-face semi-structured interview. The interview schedule (Appendix N) was based around participants' experiences of a recent incident of care-recipient behaviour they tended to find Challenging. It was developed in order to gather information about participants' attributions, emotions and responses to this behaviour and was adapted from Todd and Watts (2005), using supplementary questions so that the Leeds Attributational Coding System (LACS; Stratton, Munton, Hanks, Heard & Davidson, 1988) could

be applied to it. The LACS was developed by the Leeds Family Therapy & Research Centre and measures established constructs within attributional theory (for example beliefs regarding the controllability and stability of a cause and event). It is considered to have greater validity than forced-choice measures because it allows for the analysis of spontaneous speech provided by the participant. This provides more complex and representative data, reducing researcher bias (Snow, Langdon & Reynolds, 2007).

The researcher received training in attribution extraction and coding from a LACS-trained researcher. Causal statements were extracted from the interview transcripts and coded according to the LACS manual (Stratton *et al.*, 1988). Attributions were coded using a binary system according to controllable-uncontrollable and stable-unstable dimensions (see Appendix Q for definitions). A score of 1 was given to controllable or stable attributions, a score of 0 to uncontrollable or unstable attributions, and a score of 9 if the attribution was 'unknown'.

Initial overall agreement with a LACS-trained professional for attribution extraction (the identification of attributions to later code) across a sub-sample of five transcripts was 66%. Agreement ranged from 44% (participant 034) to 90% (participant 034) and so attributions were re-extracted. Inter-rater reliability of attribution coding with a LACS-trained professional was calculated for 60 attributions taken from nine randomly selected transcripts. Cohen's Kappa was 0.839 for controllability and 0.733 for stability, establishing excellent and good levels of reliability for attribution coding respectively (Fleiss, 1981).

Emotional response

Emotional response was measured using a 7-point itemised rating scale ranging from 1 ("Not at all") to 7 ("Extremely") (Dagnan, Trower & Smith, 1998). Target words synonymous with both sympathy and anger were selected by participants themselves from a list (Appendix O) developed as part of service-user involvement within an older adult psychology service in the north of England. The psychometric properties of these measures are unknown. However they have been deemed an acceptable measure of emotional response in this research area (Dagnan *et al.*,

1998; McGuiness & Dagnan, 2001; Hill & Dagnan, 2002; Dagnan & Cairns, 2005) and were convenient for participants to complete.

Optimism

Optimism was measured using a 7-point itemised rating scale based on those used by Dagnan *et al.* (1998) and Sharrock *et al.* (1990). Optimism was measured in reference to the reported episode of CB; participants were asked to rate their confidence in being able to manage the CB in the future from 1 (“Not at all confident”) to 7 (“Extremely confident”). This measure was selected in favour of a standardised measure of optimism due to its ecological validity and focus on specific responses to the target CB, rather than measuring a general trait. The psychometric properties of this measure are unknown.

Helping behaviour

Propensity to help at the time of the reported incident of CB was measured using two 7-point itemised rating scales based on those used by Dagnan *et al.* (1998) and Sharrock *et al.* (1990). Participants were first asked to rate their willingness to expend extra effort in order to help the care-recipient change the behaviour from 1 (“No extra effort at all”) to 7 (“As much extra effort as possible”). Using the second scale, participants rated their willingness to try different approaches to help the care-recipient change their behaviour from 1 (“Not at all willing”) to 7 (“Extremely willing”). The terminology included an intention to change the care-recipient’s behaviour in order to improve validity of measuring a *helping* behaviour to address Winer and Smith’s (2008) critique of previous research helping behaviour.

The psychometric properties of these types of itemised rating scales are unknown but they have been routinely used in other research into Weiner’s (1985) model (Dagnan *et al.*, 1998; Sharrock *et al.*, 1990; McGuiness & Dagnan, 2001; Hill & Dagnan, 2002; Wanless & Jahoda, 2002; Dagnan & Cairns, 2005). The wording of these measures was adapted for the present study in an attempt to overcome the limited validity of the aforementioned studies and the criticisms voiced by Wilner and Smith’s (2008). In the present study, Spearman’s Rho

correlation co-efficient for the two willingness to help items was 0.524 ($p=0.000067$), suggesting good levels of construct validity for this measure.

Perceived level of challenge

Perceived level of challenge was measured using the Revised Memory and Behavior Problems Checklist (R-MBPC; Teri *et al.*, 1992). This established instrument provides assessments of the frequency of CB and the perceived impact of this on the caregiver. Cronbach's Alpha scores for memory problems, disruptive behaviours, depression and total scores are 0.55, 0.66, 0.75, and 0.78 respectively when considering behaviour frequency, and 0.81, 0.73, 0.81 and 0.87 for impact upon the caregiver (Roth *et al.*, 2003).

Procedure

Participants were initially contacted by NHS clinicians (Clinical Psychologists and Community Mental Health Team staff) who were appraised of the inclusion and exclusion criteria for the study. Potential participants were made aware of the proposed research project using information sheets and consent was sought for their contact details to be passed on to the researcher. Potential participants were also identified through a database of participants taking part in a large-scale research project including family caregivers and through local organisations (e.g. Alzheimer's Society branches) and events. Once contacted by the researcher, participants were given a research pack including a participant information sheet, consent form, demographic questionnaire and R-MBPC. Participants were then contacted a week later in order to confirm their interest in taking part and to make arrangements for the interview component of the study.

Once full written consent was gained, participants took part in a 10-minute semi-structured interview either at their home or within an NHS outpatient setting and remaining self-report measures were completed. The interview was based around a recent example of the behaviour which the participant rated as being the most challenging for them on the *Reaction* scale on the R-MBPC. If multiple items were marked as equally challenging then participants were asked to select which behaviour they typically experience as the most upsetting or bothersome for them.

Interviews were digitally audio-recorded and transcribed so that the LACS could later be applied. Finally, participants completed the itemised rating scales described above. Emotional response items were administered alternately to prevent order effects.

Data analysis

Proportional attribution (PA) scores were calculated for the controllable and stable attributions provided by each participant (for more information see Barrowclough, Johnston & Tarrier, 1994; Tarrier *et al.*, 2002). This provided a measure of the extent to which all events provided by a participant tended to be attributed as being either controllable or stable. A combined PA for uncontrollable and stable was also calculated. These PA scores were included within a multiple regression analysis with the other variables. This analysis was based upon Baron and Kenny's (1986) mediator model. According to the model, data was tested to see if it was normally distributed. As the distribution was not normal and skewness and kurtosis were present, step-wise regression analyses, using bootstrapping, were conducted. Partial correlation analyses using Spearman's Rho (due to the non-parametric data) were used to support this analysis and investigate mediator relationships.

Results

Caregiver demographics

The sociodemographic characteristics of participants are presented in Table 1. The mean age of family caregivers was 66.79 years old ($SD=11.00$). Caregivers tended to be female (71.2%) spending an average of 87.79 hours per week ($SD=66.06$) providing care for their spouse/relative with dementia. Participants had spent a mean time of 45.12 months ($SD=27.04$) providing care for their family member.

Care-recipient demographics

The characteristics of care-recipients are also presented in Table 1. The mean age of care-recipients was 79.82 years old ($SD=6.62$). Care-recipients were fairly evenly split between male and female (46.2% Vs 53.8% respectively). The most

prevalent dementia diagnosis was Alzheimer's (42.3%), followed by vascular disease (25%). A large proportion of participants were unable to provide the care-recipient's diagnosis (21.2%). There was a large range of time since diagnosis (3-300 months) with the mean time since diagnosis being 46.33 months ($SD=49.48$).

Table 1. Sample Characteristics

| | <i>n</i> | % | M | SD | Range |
|-------------------------------|----------|------|-------|-------|-------|
| Caregiver | | | | | |
| Age | 52 | | 66.79 | 11.00 | 38-84 |
| Gender | | | | | |
| Male | 15 | 28.8 | | | |
| Female | 37 | 71.2 | | | |
| Time Caring (months) | 52 | | 45.12 | 27.04 | 6-144 |
| Care hours (per week) | 50 | | 87.79 | 66.06 | 4-168 |
| Care-recipient | | | | | |
| Age | 52 | | 79.82 | 6.62 | 66-96 |
| Gender | | | | | |
| Male | 24 | 46.2 | | | |
| Female | 28 | 53.8 | | | |
| Illness | | | | | |
| Alzheimer's | 22 | 42.3 | | | |
| Vascular | 13 | 25 | | | |
| Frontal | 2 | 3.8 | | | |
| Parkinsonian | 1 | 1.9 | | | |
| Mixed | 3 | 5.8 | | | |
| Unknown | 11 | 21.2 | | | |
| Time since diagnosis (months) | 51 | | 46.33 | 49.48 | 3-300 |
| Relationship to caregiver | | | | | |
| Husband | 21 | 40.4 | | | |
| Wife | 11 | 21.2 | | | |

| | | | | | |
|-------------|----|------|--|--|--|
| Father | 3 | 5.8 | | | |
| Mother | 15 | 28.8 | | | |
| Grandmother | 1 | 1.9 | | | |
| Other | 1 | 1.9 | | | |

Relationships between caregivers and care-recipients

A pattern of cross-gender caring was observed. All male caregivers provided care for a female relative with dementia (the majority of these, 66.7%, provided care for their wives). Female caregivers tended to provide care for males (64.9%) with over half of these being their husband (56.8%). In total, 61.6% of participants provided care for a spouse; 34.6% for a parent; and 3.8% for another relative.

Attributions

A total of 343 causal attributions were extracted across the 52 interviews. An average of 6.60 attributions were extracted per participant ($SD=3.86$; Range=1-19). Participants tended to attribute CB to uncontrollable (82.80%) and stable (65.31%) factors.

Perceived challenge

The mean frequency score of CBs as measured by the R-MBPC was 40.79 ($SD=14.84$; Range=8-73). The mean participant rating of subjective reaction to CB was 28.98 ($SD=15.15$; Range=1-66).

The top three CBs identified using the R-MBPC, in terms of caregiver reaction, were: arguing, irritability and/or complaining ($n=7$; %=13.5); asking the same question over and over ($n=6$; %=11.5); and engaging in behaviour potentially dangerous to self or others ($n=6$; %=11.5).

Correlational analyses

Tests of normality using the Shapiro-Wilk method revealed that independent, mediator and dependent variables were not normally distributed (see Appendix R) and thus non-parametric testing was used. Table 2 presents a cross-tabulation of the Spearman's Rho correlations between key variables investigated in this study.

Regarding the primary hypothesis of the study, significant correlations were only found between controllable attributions and anger (Spearman's $Rho=0.427$; $p=002$), sympathy and willingness to expend extra effort (Spearman's $Rho=0.388$; $p=004$), and sympathy and willingness to try different approaches to change the care-recipient's behaviour (Spearman's $Rho=0.528$; $p=000058$). Thus correlational analysis did not provide support for all of the relationships within Weiner's (1985) attributional model of helping behaviour. There was no statistical support for any of the six secondary hypotheses of the study; no significant relationships were observed between attributions and propensity to help or attributions and perceived level of challenge.

Table 2. Correlations of main variables.

| Variable | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--|--------|--------|-------|--------|--------|--------|-------|
| 1. PA controllable | | | | | | | |
| 2. PA stable | | | | | | | |
| 3. Anger | 0.427* | -0.089 | | | | | |
| 4. Sympathy | -0.006 | -0.011 | | | | | |
| 5. Optimism | -0.215 | 0.015 | | | | | |
| 6. Willingness to expend extra effort | -0.166 | -0.175 | 0.044 | 0.388* | 0.199 | | |
| 7. Willingness to try different approaches | 0.020 | -0.040 | 0.210 | 0.528* | 0.129 | 0.524* | |
| 8. Perceived challenge | 0.056 | -0.234 | 0.137 | 0.084 | -0.196 | -0.060 | 0.101 |

Note: * $p<0.001$

PA=Proportional Attribution

Testing Weiner's (1985) attributional model of helping behaviour

The primary and secondary hypotheses (1 and 2) were investigated using multiple regression analyses, in line with Baron and Kenny's (1986) mediator model. As data was not normally distributed (see above), bootstrapping was conducted on all regression analyses. The strength of the relationships between key variables associated with the primary hypothesis are presented in Figures 2-4. Willingness to expend extra effort in order to help the care-recipient change their behaviour was

selected as the key dependent, as this measure showed greater variability than willingness to try different approaches, and the two measures correlated highly (Spearman's $Rho=0.524$; $p=0.000067$).

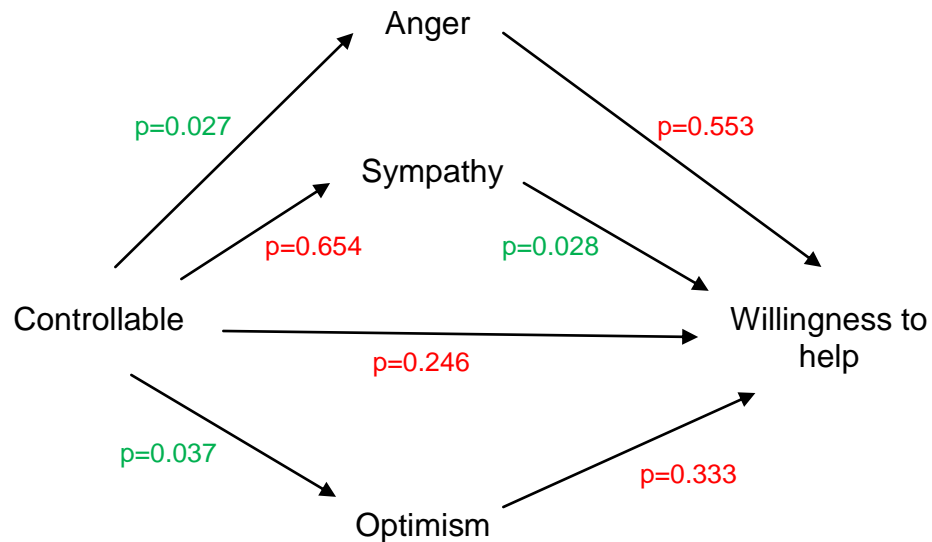


Figure 2. Regression analysis testing Weiner's (1985) model with respect to attributions of controllability only.

Note: p-values in green are significant at $p<0.05$

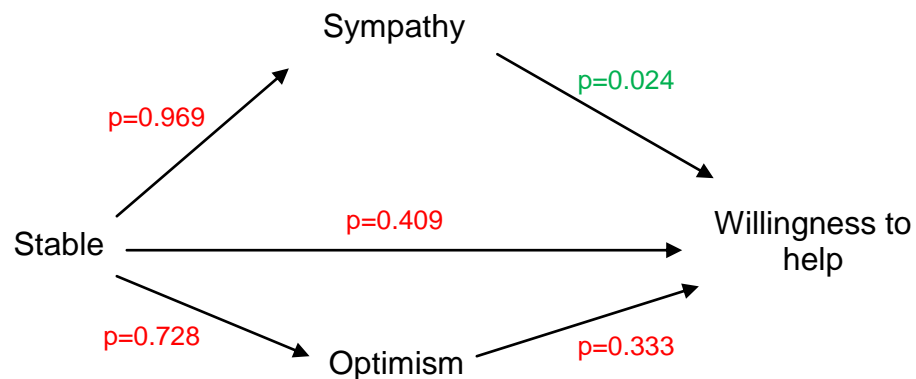


Figure 3. Regression analysis testing Weiner's (1985) model with respect to attributions of stability only.

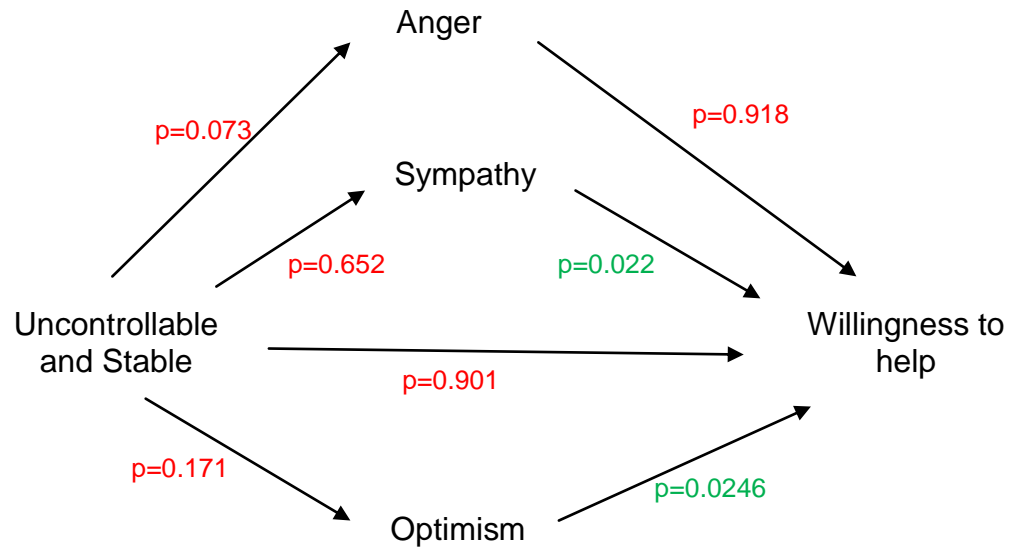


Figure 4. Regression analysis testing Weiner's (1985) model with respect to attributions of CB as both uncontrollable and stable.

As can be seen from Figures 2-4, no clear support was not found for Weiner's (1985) cognitive-emotional attributional model of helping behaviour when applied to family caregivers of IWD in the present study. Regressing the dependent variable of willingness to help onto the independent variable of controllability, stability, and a combined PA of uncontrollable and stable attributions did not result in a statistically significant main effect ($R^2=0.036$; $\beta=-1.543$; $p=0.246$; $SE=1.289$), ($R^2=0.014$; $\beta=-0.771$; $p=0.409$; $SE=0.890$) and ($R^2=0.022$; $\beta=0.100$; $p=0.901$; $SE=0.688$) respectively. Thus no evidence was found supporting Hypothesis 1; attributions of a behaviour as uncontrollable and stable will predict an increased propensity to help; or Hypothesis 2; attributions of a behaviour as controllable and unstable will predict a decreased propensity to help.

Some relationships within the model were statistically significant, however. As can be seen in Figure 2, controllable attributions did significantly predict levels of anger ($R^2=0.127$; $\beta=2.272$; $p=0.027$; $SE=1.012$). However, this was not found to mediate any relationship between controllable attributions and willingness to help. Participants scoring higher on sympathy reported greater propensity to help when all attributions were entered into the model. Again, no support was found for

sympathy having a mediating role due to the lack of a statistically significant relationship between attributions and helping behaviour.

Optimism

Hypothesis 3 stated that optimism will mediate the relationship between attributions and helping behaviour. Figure 2 shows that attributions of a behaviour as uncontrollable predicted increased optimism that a behaviour will be manageable in the future ($R^2=0.071$; $\beta=-2.175$; $p=0.037$; $SE=1.027$). Neither of these variables were found to have a direct main effect on willingness to help. However, Figure 4 demonstrates that when participants made a combination of uncontrollable and stable attributions, increased optimism was found to predict greater willingness to help ($R^2=0.089$; $\beta=0.191$; $p=0.0246$; $SE=0.159$). Despite this, optimism was not significantly associated with these attributions when combined or a relationship between attribution and helping behaviour. Consequently a mediating role for optimism was not found.

Attributions and perceived challenge

Hypotheses 4-6 concerned whether a family caregiver's perception of the challenge presented by a CB could be predicted by the attributions they made, and whether emotional response or optimism mediated this relationship. None of the regression analyses or correlational analyses including R-MBPC scores measuring perceived challenge produced statistically significant results ($p\text{-values all}>0.05$). Therefore no support was found for these hypotheses.

Discussion

The primary objective of this study was to test whether Weiner's (1985) cognitive-emotional attributional model of helping could be applied to the helping behaviour of family caregivers of IWD. It was hypothesised that emotional response would mediate a relationship between attributions and propensity to help. Overall, the multiple regression analyses did not provide support for the role of attributions in predicting the willingness to help amongst family caregivers of IWD. Consequently,

there was no clear relationship between these two factors for emotional response or optimism to mediate. This meant that the primary hypothesis could not be retained on the strength of the present findings.

Key Findings and Conceptual Issues

This study replicated some of the findings of Todd and Watts (2005) who also reported a role for optimism and sympathy in the caregiving process amongst professional caregivers and clinicians. In the present study, there was evidence that when family caregivers attributed CB to uncontrollable factors, they were more optimistic, i.e. had greater self-efficacy regarding their ability to manage CB in the future. Optimism was, however, not found to directly influence propensity to help. In contrast to the findings of Todd and Watts, attributions of CB to controllable factors was found to predict anger amongst family caregivers, however anger was not found to directly influence propensity to help. In this study, there also appeared to be a link between self-reported sympathy and willingness to help. This suggests that greater levels of sympathy are associated with increased willingness to help amongst family caregivers, as well as the professional caregivers who took part in Todd and Watt's study. Other previous work in professional dementia care has been equivocal as to the links between attributions, emotions and helping behaviour. Fopma-Loy and Austin (1997) reported that attributions of self-feeding behaviour to unstable factors and helping behaviour were strongly correlated amongst paid dementia caregivers, but no role was found for emotional response. Emotional responses and caregiving behaviours were however demonstrated to be related to attributions of controllability by Dagnan, Grant and McDonnell (2004). This suggests an important, but as yet not fully understood role for attributions of controllability and stability.

The current findings may be understood conceptually in terms of the suitability of the model investigated. From a theoretical perspective, it may be that Weiner's (1985) model of helping behaviour is not a valid model for understanding the caregiving process between family caregivers and IWD. As outlined above, existing research evidence in dementia care and in the LD field provides inconsistent, and, arguably, weak evidence for the application of Weiner's model to

caregiving in these contexts. Examination of some of the responses provided by participants in this study further illustrates this possibility and may highlight some problems with Weiner's attributional model within the context of family caregiving in dementia. For example, not all attributions of controllability are likely to increase anger. An attribution of controllability could in fact lead to increased sympathy if the intention is perceived to be good. For example, Participant 049 stated: "...he thinks it's for me; helping me you see". This indicates that the attribution component of Weiner's model may be too reductionist and that once an attribution of controllability is made, further understanding of beliefs regarding intentionality must be established in order to predict emotional responses and/or helping behaviour.

There may be additional variables specific to the relationship between caregiver and care-recipient within this context which impact upon one's willingness to help. Weiner's attributional model originated from research into altruistic acts between individuals unrelated and unknown to each other, e.g. university students (Weiner, 1980). As discussed by Todd and Watts (2005), greater personal involvement on the part of caregivers could lead to less reliance upon attributions in order to engage in helping behaviour. This could be even greater within familial relationships where stable factors relating to relationships between caregivers and IWD could be more heavily involved in the familial caregiving process.

An individual's overall caregiving style may be one such important factor. Corcoran (2011), for example, found that 'facilitating' caregivers engage in more collaborative and one-to-one helping behaviours. This style may be more associated with engagement in behaviours intended to reduce future occurrences of CB and improve emotional health. Alternatively, a family caregiver with a 'balanced' style may be more likely to aim to meet the minimum requirements of supporting an IWD rather than help change future behaviours. 'Advocating' and 'directing' caregiving styles were described in Corcoran's study as being more commonly associated with indirect helping and could, conceivably, result in less self-reported willingness to help. Whether these styles do correspond with willingness to help would be an interesting question to address in future research.

A further possibility is that helping behaviours and caregiving self-efficacy are related to pre-existing relationship quality, motivation and/or meaning ascribed to providing care. A systematic review of the literature by Quinn, Clare and Woods (2009) found that behavioural problems and functional impairment are associated with family caregiver's perceptions of relationship quality with the care-recipient. Relationship quality was found to be positively associated with caregiver wellbeing but it is unknown how this may in turn influence the caregiver willingness to help. Future research should explore this question.

Pearlin, Mullan, Semple and Skaff's (1990) stress-process model provides a way of understanding the caregiving process by accounting for factors such as coping style, relationship quality and also illness perceptions. Using this model, propensity to help could be understood in terms of a process including individual factors, the relationship between caregiver and care-recipient before and after the onset of dementia, and changes to the identity of the caregiver given their new role both as an individual and as a member of the family. The relationship between these factors and caregiver outcomes (e.g. burden) is said to be mediated by caregiver appraisals, coping style, self-efficacy and social support. Therefore this model would predict that attributions and optimism have a mediating role between a number of contextual, primary and secondary factors and help-giving behaviour, rather than attributions being directly predictive of helping behaviour with emotional response and optimism mediating this relationship as investigated within this study. Partial support was found for Pearlin *et al.*'s (1990) model when predicting family caregiver wellbeing in a systematic review of recent literature by the author of this paper (Jarvis, 2012). Future research could aim to test the validity of this model when applied to the helping behaviour of family caregivers of IWD. A key question here would be whether relationship quality changes throughout the course of the dementia, what predicts this, and whether this in turn influences caregiver appraisals and the propensity to help.

Methodological Issues

A number of methodological limitations are worth considering before firm conclusions regarding the validity of the present findings can be drawn. Firstly,

there was a large degree of skewness in the main dependent variable, willingness to help. Participants tended to rate themselves as highly willing to expend extra effort, and to try different approaches in order to help bring about change in the care-recipient's behaviour. This may be due to a social desirability bias (i.e. participants were unwilling to admit to any ambivalence about their willingness to help). Furthermore, participants volunteered to take part in this study, perhaps suggesting a selection bias, i.e. caregivers low in willingness to help would not volunteer. However, other participant characteristics may have resulted in low variation in willingness to help scores. For example, participants, in the main, provided long-term informal care for a spouse or relative and they could therefore have been subject to high levels of perceived familial obligations (see Losada *et al.*, 2010). Consequently, measuring self-reported propensity to help may be the wrong way of operationalising Weiner's (1985) model in relation to informal care in dementia. In future investigations of this kind it may be more appropriate to explore actual helping behaviours that caregivers engage in, rather than subjective perceptions of their willingness to help.

Further methodological limitations regarding sampling concern the mixture of relationships to the care-recipient and the multiple diagnoses of care-recipient dementia permitted by the inclusion criteria. Spousal caregivers may have very different relationships with the care-recipient compared with adult children (Abel, 1989) and may also have health problems affecting their responses to CB (O'Rourke, Claxton, Kupferschmidt, Smith & Beattie, 2011). The CB and care needs associated with different dementias are also likely to vary greatly. For example the demands placed upon a caregiver for someone with fronto-temporal dementia are very different to those associated with an individual with Alzheimer's disease (Mourik *et al.*, 2004). A combined sample was used here but future research should control for care-recipient characteristics in order to achieve a greater level of internal validity. As the target number of participants was not met, type two errors could have been incurred.

Whilst previous work suggests the LACS is a 'gold standard' method for measuring social attributions (Barrowclough & Hooley, 2003), several issues relating to its use in this study deserve consideration. Firstly it should be

acknowledged that initial inter-rater agreement for attribution extraction was only 66% (as low as 44% for participant 034). This highlights potential researcher bias as a confounding factor in extracting attributions using the LACS. Second, when using the LACS, it is difficult to separate cause and the effect/event of some attributions, for example memory problems or feelings of hopelessness. An example of this, taken from participant 019, is presented below:

“a general feeling that she’s in my way, holding me back and she’s bored to death, has got nothing er she’s really expecting anything else to happen except more of the same. And she doesn’t like the prospect”

Within this attribution it is difficult to separate the cause and outcome as well as the care-recipient’s beliefs about the participant. This highlights potential reliability issues with the LACS which future research of this kind should consider. i.e. that extraction of an attribution may be equivocal and subjectively interpreted in terms of whether a statement contains separate cause and effect, or whether the participant is reporting their belief or something which has been told to them.

Although the emotional response itemised rating scales are considered an acceptable measure of emotional response in this research area (Dagnan *et al.*, 1998; McGuiness & Dagnan, 2001; Hill & Dagnan, 2002; Dagnan & Cairns, 2005) and were convenient, their unknown psychometric properties are problematic for evaluation of validity and reliability. This identifies the difficulty of measuring specific emotional response to individual incidences of behaviour and the importance, in any future work, of testing the psychometric properties of scales measuring emotional response to CB.

Future Research and Clinical Implications

Based on this study and the existing literature, future work should set out to investigate alternative models to explain links between appraisals, emotions and helping behaviour in the context of dementia care in close relationships. Further work to establish the roles of coping style, relationship quality and/or changes in

relationship with the care-recipient and how this influences appraisals and helping behaviours could be useful. This may facilitate the integration of propensity to help into Pearlin *et al.*'s (1990) stress-process model of caregiving. The following research questions may be of interest in future work: How do appraisals, wellbeing and optimism influence the helping behaviours of family caregivers of IWD? Does coping style, relationship quality, or perceived change in relationship quality either directly influence helping behaviours, or mediate one of the above relationships? Can the stress-process model of caregiving be used to explain helping behaviour as well as caregiver wellbeing?

Due to the lack of evidence in support of the hypotheses of this study, it is difficult to discern clear clinical implications for this study. It is evident that the caregiving process for family members is a complicated and multi-faceted one. The finding that attributions of controllability are associated with greater family caregiver anger and that sympathy is associated with greater willingness to help suggests a need to offer appropriate support to spousal/family members through the caregiving process. This may include education programmes for caregivers around BPSD, their controllability, and what can and cannot be done to help manage these. Findings could also help inform therapeutic approaches for distressed caregivers, suggesting that cognitive-emotional or cognitive-behavioural approaches may need to pay close attention to experiences of anger and sympathy.

References

- Abel, E.K. (1989). The ambiguities of social support: Adult daughters caring for frail elderly parents. *Journal of Aging Studies*, 3, 211-230.
- Alzheimer's Research Trust. (2010). Dementia 2010: The economic burden of dementia and associated research funding in the United Kingdom. Oxford: ART.
- Alzheimer's Society. (2007). Dementia UK. London: Alzheimer's Society.
- Armor, D.A. & Taylor, S.E. (1998). Situated optimism: specific outcome expectancies and self-regulation. *Advances in Experimental Social Psychology*, 30, 309-379.
- Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, 7, 122-147.
- Baron, R. M. & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51(6), 1173-1182.
- Barrowclough, C. & Hooley, J.M. (2003). Attributions and expressed emotion: A review. *Clinical Psychology Review*, 23(6), 849-880.
- Barrowclough, C., Johnston, M. & Tarrier, N. (1994). Attributions, expressed emotion and patient relapse: An attributional model of relatives' response to schizophrenic illness. *Behaviour Therapy*, 25, 67-88.

- Boyle, G. (2010). Social policy for people living with dementia in England: promoting human rights? *Health and Social Care in the Community*, 18(5), 511-519.
- Carver, C.S., Spencer, S.M. & Scheier, M.F. (1998). Optimism, motivation, and health. In: H.S. Friedman (Ed.), *Encyclopedia of mental health* (pp. 41-52). San Diego, CA: Academic Press.
- Corcoran, M.A. (2011). Caregiving styles: a cognitive and behavioural typology associated with dementia family caregiving. *The Gerontologist*, 51(4), 463-472.
- Cunningham, C. (2006). Understanding challenging behaviour in patients with dementia. *Nursing Standard*, 20 (47), 42-45.
- Dagnan, D. & Cairns, M. (2005). Staff judgements of responsibility for the challenging behaviour of adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 49(1), 95-101.
- Dagnan, D., Grant, F., & McDonnell, A. (2004). Understanding challenging behaviour in older people; the development of the controllability beliefs scale. *Behavioural and Cognitive Psychotherapy*, 32, 501-506.
- Dagnan, D., Trower, P., & Smith, R. (1998). Care staff responses to people with learning disabilities and challenging behaviour: A cognitive-emotional analysis. *British Journal of Clinical Psychology*, 37, 59–68.
- Department of Health. (2009). *Living well with Dementia: A national dementia strategy*. London: Department of Health.
- Finkel, S. I., Costa, E., & Silva, J. (1996). Behavioural and psychological signs and symptoms in dementia – a consensus statement on current knowledge and

implications for research and treatment. *International Psychogeriatrics*, 8, 497-500.

Fleiss, J.L. (1981). *Statistical methods for rates and proportions* (2nd ed.). New York: John Wiley.

Fopma-Loy, J. & Austin, J. K. (1993). An Attributional analysis of formal caregivers' perceptions of agitated behaviour of a resident with Alzheimer's disease. *Archives of Psychiatric Nursing*, 7, 217-225.

Fopma-Loy, J. & Austin, J. K. (1997). Application of an attribution-affect-action model of caregiving behavior. *Archives of Psychiatric Nursing*, 11(4), 210-217.

Fritz, M.S. & MacKinnon, D.P. (2007). Required sample size to detect the mediated effect. *Psychological Science*, 18(3), 233-239.

Ganguli, M., Dodge, H. H., Shen, C., Pandav, R. S., & DeKosky, S. T. (2005). Alzheimer Disease and Mortality: A 15-Year Epidemiological Study. *Archives of Neurology*, 62, 779-784.

Gottlieb, B. H. & Rooney, J. A. (2004). Coping effectiveness: determinants and relevance to the mental health and affect of family caregivers of persons with dementia. *Aging Mental Health*, 8(4), 364-373.

Helzner, E. P., Scarmeas, N., Cosentino, S., Tang, M. X., Schupf, N., & Stern, Y. (2008). Survival in Alzheimer disease: A multiethnic, population-based study of incident cases. *Neurology*, 71(19), 1489-1495.

Hill, C. & Dagnan, D. (2002). Helping, attributions, emotions and coping style in response to people with learning disabilities and challenging behaviour. *Journal of Learning Disabilities*, 6(1), 363-372.

- Jarvis, A.T. (2012). *Predictors of psychological wellbeing in family caregivers of individuals with dementia –a systematic review of the literature*. Manuscript submitted for publication.
- Knapp, M., Prince, M., Albanese, E., Banerjee, S., Dhanasiri, S., Fernandez, J. L., Ferri, C., McCrone, P. & Stewart, R. *Dementia UK*. 2007. London, Alzheimer's Society.
- Larson, E. B., Shadlen, M. F., Wang, L., McCormick, W. C., Bowen, J. D , Teri, L., & Kukull, W. A. (2004). Survival after Initial Diagnosis of Alzheimer Disease. *Annals of Internal Medicine*, 140(7), 501-509.
- Losada, A., Márquez-González, M., Knight, B.G., Yanguas, J., Sayegh, P. & Romero-Moreno, R. (2010). Psychosocial factors and caregivers' distress: effects of familism and dysfunctional thoughts. *Aging and Mental Health*, 14(2), 193-202.
- McGuiness, P. & Dagnan, D. (2001). Cognitive emotional reactions of care staff to difficult child behaviour. *Behavioural and Cognitive Psychotherapy*, 29(3), 295-302.
- Mourik, J.C., Rosso, S.M., Niermeijer, M.F., Duivenvoorden, H.J., van Swieten, J.C. & Tibben, A. (2004). Frontotemporal dementia: Behavioral symptoms and caregiver distress. *Dementia and Geriatric Cognitive Disorders*, 18, 87-104.
- National Institute for Health and Clinical Excellence. (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. London: NICE.
- O'Rourke, N., Claxton, A., Kupferschmidt, A.L., Smith, J.Z & Beattie, B.L. (2011). Marital idealization as an enduring buffer to distress among spouses of

persons with Alzheimer disease. *Journal of Social and Personal Relationships*, 28(1), 117-133.

Pearlin, L.I., Mullan, J.T., Semple, S.J. & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30(5), 583-594.

Quinn, C., Clare, L. & Woods, B. (2009). The impact of quality of relationship on the experiences and wellbeing of caregivers of people with dementia: a systematic review. *Aging and Mental Health*, 13(2), 143-154.

Roth, D. L., Gitlin, L.N., Coon, D. W., Stevens, A.B., Burgio, L.D., Gallagher-Thompson, D., Belle, S.H. & Burns, R. (2003). Psychometric analysis of the Revised Memory and Behavior Problems Checklist: Factor structure of occurrence and reaction ratings. *Psychology and Aging*, 18(4), 906-915.

Sharrock, R., Day, A., Qazi, F., & Brewin, C. (1990). Explanations by professional care staff, optimism and helping behaviour: an application of attribution theory. *Psychological Medicine*, 20, 849–855.

Snow, W., Langdon, P.E. & Reynolds, S. (2007). Care staff attributions toward self-injurious behaviour exhibited by adults with intellectual disabilities. *Journal of Intellectual Disabilities*, 11(1), 47-63.

Stratton, P., Munton, A.G., Hanks, H., Heard, D.H., & Davidson, C. (1988). The Leeds Attributional Coding System (LACS) Manual. Leeds: Leeds Family Therapy & Research Centre.

Tarrier, N., Barrowclough, C., Ward, J., Donaldson, C., Burns, A., & Gregg, L. (2002). Expressed emotion and attributions in the carers of patients with Alzheimer's Disease: The affect on carer burden. *Journal of Abnormal Psychology*, 111(2), 340-349.

- Teri, L., Truax, P., Logdson, R., Uomoto, J., Zarit, S., & Vitaliano, P. (1992). Assessment of behavioral problems in dementia: the revised memory and behavior problems checklist. *Psychology and Aging, 7*, 622-633.
- Todd, S. J. & Watts, S. C. (2005). Staff responses to challenging behaviour shown by people with dementia: an application of an attributional-emotional model of helping behaviour. *Aging Mental Health, 9*(1), 71-81.
- Wanlass, L. K. & Jahoda, A. (2002). Responses of staff towards people with mild to moderate intellectual disability who behave aggressively: a cognitive emotional analysis. *Journal of Intellectual Disability Research, 46*(1), 507-516.
- Weiner, B. (1980). A cognitive (attribution)-emotion-action model of motivated behaviour: an analysis of judgements of help-giving. *Journal of Personality and Social Psychology, 39*(2), 186–200.
- Weiner, B. (1985). *An attributional theory of motivation and emotion*. New York: Springer-Verlag.
- Wilner, P. & Smith, M. (2008). Attribution theory applied to helping behaviour towards people with intellectual disabilities who challenge. *Journal of Applied Research in Intellectual Disabilities, 21*, 150-155.
- World Health Organization (1992) *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*. Geneva: WHO.

Appendix A: Instructions to contributors to *International Psychogeriatrics* for reviews of the literature

International Psychogeriatrics

Please read these instructions carefully before submitting articles. Articles which are not prepared in accordance with these guidelines will be returned to authors unreviewed.

Scope and contributions

International Psychogeriatrics is written by and for those doing clinical, teaching, and research work with elderly people. It is the official journal of the International Psychogeriatric Association (IPA) and is published by Cambridge University Press, Cambridge, UK. Although it is concerned primarily with psychogeriatrics, the journal welcomes contributions from all concerned with the field of mental health and aging. Original research papers are particularly sought.

Contributions include original research articles, reviews of the literature, “for debate” articles, case reports, letters to the editor, book reviews and editorials. Apart from editorials, “for debate” articles and book reviews, which are commissioned, contributions to *International Psychogeriatrics* are spontaneously written and submitted by authors. Papers are reviewed by at least two expert reviewers selected by the Editor-in Chief. At present about half of the papers submitted are accepted for publication in this journal which is published twelve times per annum. The journal’s Science Citation Index Impact Factor (2010) is 2.478. Submission of a paper implies that it is neither under consideration for publication elsewhere, nor previously published in English. Manuscripts must be formatted double-spaced with ample margins on all sides and the pages should be numbered. Please leave a spare line between paragraphs to enable typesetters to identify paragraph breaks without ambiguity. *International Psychogeriatrics* uses the spelling of American English. Manuscripts written by those whose primary language is not English should be edited carefully for language prior to submission. *International Psychogeriatrics* has a Language Advisory Panel of English speakers

willing to check manuscripts for style prior to submission. Details can be found at both the journal website (<http://journals.cambridge.org/ipg>) under the related links icon and the IPA website (<http://www.ipa-online.org/>).

Submission of manuscripts

Manuscripts should be submitted online via our manuscript submission and tracking site, <http://mc.manuscriptcentral.com/ipg>. Full instructions for electronic submission are available directly from this site. If you are unsure of the suitability of your manuscript, please e-mail the abstract to the Journal Office before submitting online: ipaj-ed@unimelb.edu.au To facilitate rapid reviewing, communications for peer review will be electronic and authors will need to supply a current e-mail address when registering to use the system.

When submitting your manuscript you will need to supply: A cover letter, the manuscript with the text file in MS Word format, and all figures in TIFF or JPEG format. If the paper reports the results of a randomized controlled trial please ensure that it conforms to our requirements listed below under the heading 'Submission of randomized clinical trials' on page 2. If the research was paid for by a funding organization, the cover letter must contain the following three statements (this information does not have to be included in the manuscript itself but only in the cover letter). If the research was not paid for by a funding organization only the third statement is required:

1. That the authors have not entered into an agreement with the funding organization that has limited their ability to complete the research as planned and publish the results.
2. That the authors have had full control of all the primary data.
3. That the authors are willing to allow the journal to review their data if requested.

Submission of a manuscript will be taken to imply that all listed authors have seen the final version and approved it.

All papers will be assessed by two reviewers. If their opinions are too disparate to permit the Editor-in-Chief to make a decision on publication or the reviewers are

unable to make clear recommendations, the paper will be assessed by a third reviewer. **The Editor-in-Chief's decision to accept, reject or request revision of the paper for publication will be final.** The abstract and author details will be seen by prospective reviewers of the manuscript. Authors can suggest the names and contact information of experts qualified to review the work, but the Editor-in-Chief is not obliged to follow these suggestions. Papers must bear the authors' names, titles (e.g., Dr, Professor, etc.), affiliation(s), and address(es). This information will be seen by reviewers. Reviewers' names will not be supplied to authors unless a reviewer asks to be so identified. Authors will be provided with a copyright transfer form to sign after acceptance of the manuscript, consenting to publication of the paper in *International Psychogeriatrics*.

The receipt of all submitted papers will be acknowledged. Authors who do not receive an acknowledgement of receipt of their paper within three weeks of submission should assume that their paper has not been received and should contact ipaj-ed@unimelb.edu.au, Professor Nicola Lautenschlager. Normanby House, St George's Hospital, 283 Cotham Road, Kew, Victoria, 3101, Australia, Tel: +61 3 9816 0485, Fax: + 61 3 9816 0477. Most authors can expect to receive an initial decision on the fate of their paper together with referees' reports within no more than 100 days of submission. Authors who have received no further communication 120 days after acknowledgment of receipt of their article should contact ipaj-ed@unimelb.edu.au.

Reviews of the Literature

International Psychogeriatrics will publish at least 1 literature review in each issue. Authors intending to submit a literature review should check recent issues of *International Psychogeriatrics* to ensure that no review of the topic they propose to discuss has been published in the journal in recent times. Review articles may have up to 50 relevant references. Authors contemplating the submission of a literature review article are welcome to contact the editor to discuss the appropriateness of the topic prior to submission (ipaj-ed@unimelb.edu). Literature reviews should have an abstract.

Appendix B: Guidelines for submission to Aging & Mental Health

SCHOLARONE MANUSCRIPTS™

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the [guide for ScholarOne authors](#) before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.



Aging & Mental Health welcomes original contributions from all parts of the world on the understanding that their contents have not previously been published nor submitted elsewhere for publication. We encourage the submission of timely review articles that summarize emerging trends in an area of mental health and aging, or which address issues which have been overlooked in the field. Reviews should be conceptual and address theory and methodology as appropriate. All submissions will be sent anonymously to independent referees. It is a condition of acceptance that papers become the copyright of the publisher.

Manuscripts

Manuscripts may be in the form of: (i) regular articles not usually exceeding **5,000 words** (under special circumstances, the Editors will consider articles up to **10,000 words**); or (ii) short reports not exceeding **2,000 words**. These word limits **exclude** references and tables.

All submissions should be made online at *Aging & Mental Health's* [ScholarOne Manuscripts site](#). New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre.

Authors should prepare and upload two versions of their manuscript. One should be a complete text, while in the second all document information identifying the author should be removed from files to allow them to be sent anonymously to

referees. When uploading files authors will then be able to define the non-anonymous version as "File not for review".

All submissions should be in the style of the **Publication Manual** of the American Psychological Association (6th edition, 2009). Papers should be double spaced throughout (including the references), with margins of at least 2.5 cm (1 inch). All pages must be numbered.

The first page should include the title of the paper, first name, middle initial(s) and last name of the author(s), and for each author a short institutional address, and an abbreviated title (for running headlines within the article). At the bottom of the page give the full name and address (including telephone and fax numbers and e-mail address if possible) of the author to whom all correspondence (including proofs) should be sent. The second page should repeat the title and contain **an abstract of not more than 250 words**. The third page should repeat the title as a heading to the main body of the text.

Structured abstracts: The main text should be preceded by a short structured abstract, accompanied by a list of keywords. The abstract should be arranged as follows: Title of manuscript; name of journal; abstract text containing the following headings: Objectives, Method, Results, and Conclusion.

Key words: A list of 3-5 keywords should be provided. Words already used in the title should be avoided if possible

The text should normally be divided into sections with the headings Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content. Within the text section headings and subheadings should be typed on a separate line without numbering, indentation or bold or italic typeface.

Style guidelines

Description of the Journal's [article style](#)

Description of the Journal's [reference style](#), [Quick guide](#)

Any consistent spelling style is acceptable. Use single quotation marks with double within if needed.

If you have any questions about references or formatting your article, please contact authorqueries@tandf.co.uk (please mention the journal title in your email).

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Units of measurement

All measurements must be cited in SI units.

Illustrations

All illustrations (including photographs, graphs and diagrams) should be referred to as Figures and their position indicated in the text (e.g. Fig. 3). Each should be submitted numbered on the back with Figure number (Arabic numerals) and the title of the paper. The captions of all figures should be submitted on a separate page, should include keys to symbols, and should make interpretation possible without reference to the text.

Figures should ideally be professionally drawn and designed with the format of the journal (A4 portrait, 297 x 210 mm) in mind and should be capable of reduction.

Tables

Tables should be submitted on separate pages, numbered in Arabic numerals, and their position indicated in the text (e.g. Table 1). Each table should have a short, self-explanatory title. Vertical rules should not be used to separate columns. Units should appear in parentheses in the column heading but not in the body of the table. Any explanatory notes should be given as a footnote at the bottom of the table.

Proofs

Proofs will be sent to the author nominated for correspondence. Proofs are supplied for checking and making essential typographical corrections, not for general revision or alteration. Proofs must be returned within 72 hours of receipt.

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Aging & Mental Health has a new editorial e-mail address: amh@ucl.ac.uk.

General enquires can be sent to m.orrell@ucl.ac.uk.

Appendix C: Quality Checklist

Study Assessed: _____

| Item # | Sub-section | Criteria | Yes (Score = 1) | No (Score = 0) | Unable to determine (Score = 0) | Not Applicable |
|--------|--|---|--------------------|-------------------|---------------------------------------|----------------|
| 1 | Abstract | Abstract gives clear and balanced informative account of what was done and the major findings | | | | |
| | Introduction | | | | | |
| 2 | Background and rationale | An explicit theoretical framework given and rationale for the research reported | | | | |
| 3 | Objectives | Aims, objectives and/or hypotheses clearly stated | | | | |
| | Method | | | | | |
| 4 | Study design | A clear exposition of the study design is given | | | | |
| 5 | Participants | Eligibility criteria reported and clear explanation of how participants were recruited | | | | |
| 6 | Sampling bias | Researchers made reasonable attempt to recruit participants from large and varied (representative) source | | | | |
| 7 | Variables | Clearly defines all outcomes and independent variables. Gives diagnostic criteria if applicable. | | | | |
| 8 | Data sources/ measurement -Reliability | Sources of data and methods of assessment are reported and reliability statistics are reported. | | | | |
| 9 | Data sources/ measurement -Validity | Main outcome measures used are accurate and validated | | | | |
| 10 | Statistical methods | Statistical tests appropriate and replicable | | | | |
| | Results | | | | | |

| | | | | | | |
|--------------------|--------------------------------------|---|--|--|--|--|
| 11 | Descriptive data -Participants | Gives characteristics of study participants and information on potential confounders | | | | |
| 12 | Descriptive data -Care-recipients | Characteristics of the care-recipients defined including age, type of dementia, and relationship to the participant. | | | | |
| 13 | Power calculation/ sample size | Study has sufficient power to detect significant effect at $p < 0.05$ or justifies sample size and lack of power calculation | | | | |
| 14 | Main Results | A clear exposition of the main outcomes is given | | | | |
| 15 | Main Results | Reports actual p values for main outcomes | | | | |
| | Discussion | | | | | |
| 16 | Key Results | Clearly summarises key results with reference to theoretical framework and research objectives | | | | |
| 17 | Limitations | Discusses limitations of study including direction and magnitude of any potential biases | | | | |
| 18 | Interpretation | Gives a cautious overall interpretation of results in respect to the theoretical framework, objectives and limitations of the study | | | | |
| 19 | Generalisability | Discusses the generalisability/ external validity of the study | | | | |
| | Other | | | | | |
| 20 | Funding | Source of funding and role of funders given | | | | |
| Total Score | | | | | | |

Appendix D: Data Extraction Form

| Reference | Study Aim(s) | Sample | Design | Variables/ Measures | Results | Themes | Quality Rating |
|-----------|--------------|--------|--------|---------------------|---------|--------|----------------|
| | | | | | | | |

Appendix E: Approval Letter from Research Ethics Committee

-Removed for hard binding-

Appendix F: Participant Information Sheet

*We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. **The researcher will go through the information sheet with you and answer any questions you have.** We'd suggest this should take about 5 minutes. Please ask if anything is not clear.*

Family Responses to Changes in Behaviour in Dementia- Version 2.

Family members and spouses who support a person with dementia sometimes have to cope with changes in behaviour that can cause problems. These changes differ from person to person but can include aggression, repetitive questioning, wandering or withdrawn behaviour. Such problems can often be challenging to make sense of and cope with.

When faced with these problems it is natural to form ideas about why the person with dementia is acting this way and whether they can help it. These ideas are called 'attributions' by psychologists. Attributions might affect how somebody feels and reacts to changes in behaviour that can be linked with dementia. People may also think about whether they will be able to manage the behaviour of the person they support in the future. How optimistic spouses and family members feel about this might also influence how they react and cope.

What is the purpose of the study?

Some evidence suggests that the way spouses and family members think and feel when they are faced with difficult behaviours caused by dementia might affect how challenging they find them. Attributions, optimism and feelings such as sympathy might also affect how they feel about giving extra help to the person. This study will investigate these issues with family caregivers and spouses caring for someone with dementia at home. Previous research has been limited because it has only tended to involve people in care homes. It is hoped this research will increase our understanding of what it is like to cope at

home with changes in behaviour in dementia and this could improve the support that can be offered to carers and families.

Why have I been invited?

You have been invited to take part because you are a family member or spouse supporting a person with dementia. We are hoping to recruit around 60 family caregivers in total.

Do I have to take part?

No, it is up to you to decide to take part. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to stop taking part at any time without giving a reason. Whether or not you take part will not affect the standard of care the person you support receives.

What will happen if I decide to take part?

You will be asked to complete a consent form and two questionnaires (usually sent by post). We would be grateful if you could complete these at home to save time. If there is anything you are unsure about then you can bring these questions with you to the next stage of the study when you meet the researcher in person.

The first questionnaire is very short and asks for some basic details about you and the person you give support. The second one asks you about some of the behaviours or problems you may be faced with and how difficult you find them to cope with. Both questionnaires together should take no more than 20 minutes for you to complete.

You will then be invited to take part in a short, 10-minute interview with the researcher, Adam Jarvis. This can take place at your home to be convenient for you. Otherwise you can be interviewed somewhere else if you like (such as an NHS building). The interview will simply be a conversation about the most recent time you encountered one of the behaviours or problems which you identified in the questionnaire. This 10-minute interview will be tape-recorded so that, later, we can fully understand your experiences. It will not be possible to

identify you from the tape recording; you will not be asked to state your name or the name of the person you support.

Finally you will be asked to answer some very short questions about your feelings, thoughts and your willingness to help. This should take around 5-10 minutes to complete.

All in all, your participation in this research study will take up no more than an hour of your time. You will have the option to see the results of the study once it is completed.

What are the possible disadvantages and risks of taking part?

Taking part in this study requires some of your time, which may be inconvenient for you. You have the option of filling in the questionnaires at home which should save travelling time and make it as easy and comfortable for you as possible.

If the interview is not conducted at your home then you will need to remember to either post the questionnaires back to us in the free post envelope provided or bring them with you to wherever the interview is held.

It is possible that you may find some of the questions upsetting. This is because you will be asked to think about some experiences of your family member acting in a way that you find difficult. You may also be worried that you will be judged on your answers. This is a normal worry but we assure you that there is a huge range in how people respond to these kind of behaviours and that your answers will be kept anonymous and confidential.

If you become upset during or after answering any of the questions, we will encourage you to contact and talk to the researcher who can discuss options for further help and/or support if you would like.

What are the possible benefits of taking part?

We cannot promise the study will help you immediately but we do hope that the information we gather will help us understand and improve the support given to

family members and spouses of people with dementia. Many people feel they have contributed something of great importance by taking part in research. Taking part will give you an opportunity to think about your feelings and responses when providing care for your family member or spouse, and some people find that helpful.

What will happen if I decide I no longer wish to take part?

After signing the consent form, you can still change your mind about being in the study. Even if you have already given us your completed questionnaires and been interviewed you can contact us at any time and we will remove and destroy any information you have provided to us.

What if there is a problem?

If you are worried at all about anything to do with this study you should ask to speak to the researcher who will do their best to answer your questions [07971969149]. If you ever want to make a formal complaint, you can do this through the NHS Complaints Procedure. Details can be obtained from the Patient Advice and Liaison Service (PALS) at the main reception desk of your nearest hospital.

Will my taking part in this study be kept confidential?

All data will be handled ethically and legally. All information which is collected about you during the course of the research will be anonymised which means no names or personal details will be attached to it. Your interview will be typed up and anonymised using a computer. Once this is done, the audio recording will be destroyed. Your questionnaire and interview will be given a code number which will be used throughout the analysis of the results. This coded data will be stored securely at the University of Hull for five years after the study has finished before it will be destroyed

The only exception to this is if you say something that makes the researcher concerned that you or anybody else may be at risk; for example, if you say that you are feeling that life is not worth living. If this happens then the researcher will discuss with you what would need to happen next and usually this would involve supporting you to contact your GP and/or local services that could help you.

What will happen to the results of the study?

The results will be written up as part of a thesis for a doctoral qualification. It is also intended that the study will be published in a scientific journal. Single quotes from your interview may be included in the writing up of the study but you will not be named or made personally identifiable in any way. Information about the results of the study will be available from the researcher when the study is completed in Summer 2012.

Who is organising and funding the research?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded through the University of Hull.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee. This makes sure that your interests are protected. This study has been reviewed and given a favourable opinion by the Research Ethics Committee.

Further information and contact details

If you have any further questions or queries, please contact Adam Jarvis (see below) either in person in the clinic or on 07971969149 between the hours of 9:30am and 4:30pm.

Alternatively, the academic supervisor of the project, Dr Chris Clarke, can also be contacted at the University of Hull on 01482 464106 or, preferably, at

c.clarke@hull.ac.uk

Adam Jarvis

Department of Clinical Psychology

Hertford Building

University of Hull

Cottingham Road

Hull

HU6 7RX

Appendix G: Brief Participant Information Sheet

Clinical Psychology Research Project: **Family Responses to Changes in Behaviour in Dementia**

Full title: Family Caregiver Responses to Challenging Behaviour in Individuals with Dementia
Doctoral Level Research – Hull / York Clin. Psy. D. Programme, University of Hull.

We are looking for family members or spouses who support a person with dementia to take part in this research, which aims to investigate the way spouses and family members think, feel and act when they are faced with difficult behaviours caused by dementia.

We are continuing to recruit participants to the study until February 2012. We are looking for spouses and / or family members:

- Who have been helping to support somebody with a diagnosis of dementia for at least 2 months.
- Who are not paid/professional caregivers.
- Who speak fluent English.
- Where the person with dementia is aged 65 or over.

If you decide to take part you will be asked to fill out three brief questionnaires and have a very short interview with the researcher (10 minutes). The whole process takes no longer than 1 hour and you would be seen in your own home or a location convenient for you.

If you are interested in taking part in the research and would like to receive a full information sheet then please pass your details onto the researcher using the details below:

Adam Jarvis
Trainee Clinical Psychologist
Department of Clinical Psychology and Psychological Therapies
University of Hull
Hertford Building
Hull, HU6 7RX
Tel. **07971 969149**
Secure NHS Email: adam.jarvis@nhs.net

Thank you very much for your interest!

Appendix H: Consent Form for Transfer of Contact Details

Participant Identification number for this study:

CONSENT FORM

Title of project: Family Caregiver Responses to Challenging Behaviour in Individuals with Dementia

Name of Researcher: Adam Jarvis (Trainee Clinical Psychologist)
 Department of Clinical Psychology and Psychological Therapies, University of
 Hull, Hull, HU6 7RX
 Tel. **07971 969149**
 Email: adam.jarvis@nhs.net

| | <u>Please initial the box</u> |
|--|-----------------------------------|
| 1. I confirm that the below contact details belong to me | <input type="checkbox"/> |
| 2. I agree that my contact details may be passed on to the researcher so that they may contact me to provide me with more information about the above study. | <input type="checkbox"/> |

I would like to be contacted using the details given below:

.....

.....

.....

.....

.....

.....

 Name of interested party

 Date

 Signature

 Name of person
 Taking consent

 Date

 Signature

Appendix I: Covering Letter for Research Pack

Adam Jarvis
Department of Clinical Psychology
Hertford Building
University of Hull
Cottingham Road
Hull
HU6 7RX
Tel. **07971 969149**
Secure NHS Email: adam.jarvis@nhs.net

Dear [participant],

Please find enclosed the full information pack for the research project we discussed. Also included are the consent form for taking part in the study and two of the questionnaires used as part of the research. If you have any queries about any of the forms or questionnaires including how to complete them then please do not hesitate to contact me using the above details.

It may save you time to complete the forms before meeting to complete the 10-minute interview and final short questionnaire. If you would prefer me to go through the forms with you then that is absolutely fine.

Many people find it most convenient to complete the interview at their own home, however if you would prefer this to take place at another venue then that is no problem; just let me know.

Feel free to contact me when you are ready to make arrangements for the interview part of the study. If I have not heard from you within a week or so of sending out this letter then I will give you a phone call just to check if you would still like to take part in the study and make further arrangements if appropriate.

Many thanks for your continued interest in this project.

Yours sincerely,

Adam Jarvis
Trainee Clinical Psychologist

Appendix J: Consent Form

Participant Identification number for this study:

CONSENT FORM

Title of project: Family Caregiver Responses to Challenging Behaviour in Individuals with Dementia

Name of Researcher: Adam Jarvis

**Please initial
the box**

| | |
|---|--------------------------|
| 1. I confirm that I have read and understand the information sheet dated 1 April 2011 (version 2), for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any medical care or legal rights being affected for me or the person I provide care for. | <input type="checkbox"/> |
| 3. I am aware of the potential risks and benefits of taking part. | <input type="checkbox"/> |
| 4. I agree to take part in the above study | <input type="checkbox"/> |

| | | |
|----------------------------------|-------|-----------|
| _____ | _____ | _____ |
| Name of participant | Date | Signature |
| | | |
| _____ | _____ | _____ |
| Name of person Taking consent | Date | Signature |

Appendix K: Demographic Questionnaire

About you:

Sex (tick box as appropriate): Male ☐ Female ☐

Age:.....

How long (in months) have you been providing care for your family member)?

.....

How many hours per week do you spend providing care for your family member (on average)?

Please list the types of support you provide for your family member (e.g. personal care like washing and brushing teeth, cooking, washing etc.):

.....

About the person you provide care for:

Sex (tick box as appropriate): Male ☐ Female ☐

Age:.....

Time (in months) since diagnosis of dementia:

Type of dementia diagnosed (if known):

What is the relationship of this person to you (e.g. husband, wife, mother, father, brother, sister etc.)?

For Researcher use only:

Participant Identification Number.....

Appendix L: Revised Memory and Behavior Checklist

-Removed for hard binding-

Appendix M: Consent Form for Audio Recording of Interview

Participant Identification number for this study:

Pseudonym Used (If any):

CONSENT FORM FOR AUDIO RECORDING

Title of project: Family Caregiver Responses to Challenging Behaviour in Individuals with Dementia

Name of Researcher: Adam Jarvis

**Please initial
the box**

| | |
|---|--------------------------|
| 1. I confirm that I have been informed that the interview portion of this study will be digitally recorded using a Dictaphone. | <input type="checkbox"/> |
| 2. I confirm that I have been asked to not give any personally identifiable information during the interview, and to use a pseudonym if preferred. | <input type="checkbox"/> |
| 3. I understand that this recording will be transcribed and anonymised using a computer and once this transcription is completed the audio recording will be destroyed. | <input type="checkbox"/> |
| 4. I agree that the interview conducted with me as part of this study may be recorded. | <input type="checkbox"/> |

Name of participant

Date

Signature

Name of person
Taking consent

Date

Signature

Appendix N: Interview Schedule

"I will be asking several questions about your views and experiences of the problem which you have described as being most challenging for you. Please answer in as much detail as you can. Please try **not** to provide any information which would make yourself or the person you care for identifiable such as names or addresses. Do you have any questions before we begin?"

1. "When was the last time you witnessed the person you care for [performing identified challenging behaviour]?"
2. "Could you describe the behaviour and what happened in as much detail as possible for me please?"
3. "What are your thoughts about the reason these behaviours might have occurred?"

(If response describes account from somebody else's point of view or is considered short the following prompt will be given)

"Can you tell me more about what you mean?"

4. "Could you explain in as much detail as possible what you did in response to this behaviour on this occasion?"
5. "What if anything do you think would help to reduce this behaviour shown by the person you care for?"
6. "Thank you for completing this part of the project. Are there any questions you have at this stage?"

END OF INTERVIEW

Appendix O: Emotional Responses Selection

Participant Identification Number:

INSTRUCTIONS

Please select the word which best describes the emotion you felt when this behaviour occurred:

Angry
Irritated
Agitated
Annoyed
Offended
Frustrated
Disgusted
Resentful
Repulsed
Incensed
Enraged
Seething
Infuriated
Grumpy
Boiling
Fuming
Cross

Sympathetic
Pitiful
Sorry
Compassionate
Empathetic
Warmth
Own Word: _____

Own Word: _____

Appendix P: Self-Report Measures

Participant Identification Number:

Willingness to help, optimism and emotional response questionnaire

Please indicate your responses by circling the number which best describes how you feel.

1. How much extra effort would you be willing to give to help this person change their behaviour?

No extra effort at all 1 2 3 4 5 6 7 As much extra effort as possible

2. How willing would you be to try different approaches to help this person change their behaviour?

Not at all willing 1 2 3 4 5 6 7 Extremely willing

3. How confident are you that this particular behaviour will be manageable in the future?

Not at all confident 1 2 3 4 5 6 7 Extremely confident

4. How do you feel about the behaviour you encountered? Rate your emotional reaction by circling a number from 1 to 7.

Not at all [angry] 1 2 3 4 5 6 7 Extremely [angry]

Not at all [sympathetic] 1 2 3 4 5 6 7 Extremely [sympathetic]

Appendix Q: Attribution Definitions

Causal attribution

A statement which contains a causal factor, an event (or outcome) and a link between this cause and event. The attribution must be made by the participant and not somebody else.

Controllable-uncontrollable dimension

The controllable-uncontrollable dimension refers to the cause, event and the link between these two factors. An attribution is controllable (thus given a score of 1) if the participant believes that the care-recipient could have influenced the outcome without having to exert exceptional effort. If the participant believes the process leading to the event was inevitable then the attribution is coded as uncontrollable (and given a score of 0).

Stable-unstable dimension

The stable-unstable dimension refers to the cause of the target behaviour. An attribution is coded as stable (thus given a score of 1) if the cause is likely to influence future events and not change in the short-term. An attribution is coded as unstable (and given a score of 0) if it is unlikely to influence future events or change in the short-term.

Appendix R: Tests of Normality

| Tests of Normality | | | | | | |
|--|---------------------------------|----|------|--------------|----|------|
| | Kolmogorov-Smirnov ^a | | | Shapiro-Wilk | | |
| | Statistic | df | Sig. | Statistic | df | Sig. |
| Proportional attributions: Controllable | .313 | 52 | .000 | .768 | 52 | .000 |
| Proportional attributions: Stable | .139 | 52 | .014 | .921 | 52 | .002 |
| ExtraEffort | .261 | 52 | .000 | .803 | 52 | .000 |
| DifferentApproaches | .374 | 52 | .000 | .688 | 52 | .000 |
| Optimism | .224 | 52 | .000 | .895 | 52 | .000 |
| Anger | .132 | 52 | .025 | .950 | 52 | .029 |
| Sympathy | .219 | 52 | .000 | .851 | 52 | .000 |

a. Lilliefors Significance Correction

Reflective Statement

Introduction

This reflective statement aims to provide an insight as to the reflective process undertaken by the researcher throughout the course of the research project. It is a personal account of the project, including preliminary research, conceptualisation, operationalisation, conduction and write-up. Also included is reflection on how the experience of the present research project will influence future work by the researcher.

Background

I wanted to carry out a research project into an area which is clearly of relevance within the current context of Psychology and mental health. I was concerned that if I were to undertake a research project purely on the premise of fulfilling the requirements of a Clinical Psychology doctorate then this would not be enough to maintain my motivation and engagement with the project throughout the three years, and thought that it was important to try to challenge myself. I had an awareness of the growing prevalence of dementia and the demands this places on the family from experience within my own family. Being appraised of the relative lack of research within this field by my supervisor made it seem a good area to base my thesis on given the above.

Planning and Design

One disadvantage of a smaller literature base surrounding the caring behaviours of spouse or family members of relatives with dementia was that it was difficult to select which model to investigate within the empirical study. There were generally more models available to understand the burden placed upon family caregivers than the helping behaviour they engage in. The Todd and Watts (2005) paper testing Weiner's (1985) attributional model of helping behaviour amongst professional care staff of people with dementia seemed like a good starting point. I felt slightly uncomfortable testing a model from 1985, as I felt like I should be investigating more contemporary theory. After reflecting on this for a while, I started to move toward a stance of curiosity: If this model has been around for so long, why has it never been tested amongst family caregivers of individuals with dementia? What happens if well established models go unexamined within important populations for a long period of time? If

too long passes, do these theories get put on the shelf; often cited but never explored as researchers believe they have gathered too much dust? It occurred to me that even if a model is twenty-five years old, if it is one of great significance then it be put to test, even if the findings mean that the need to search for a new model is revealed.

Once a model was arrived upon, the design of the study took place. This took shape quite naturally following a critical review of previous literature within the area, and understanding of what elements of the research design should be retained (e.g. the Leeds Attributional Coding System, as it is the considered the 'gold standard' for investigating attributions). As in clinical work, the approach taken to the design methodology had to be justified in terms of an evidence base; in this case previous research in the related literature. Although it may have been found that this was not the best design for this particular research project, it could reveal how future research should be re-designed, much like how clinical work with a client may have to be re-formulated. Although this helped raise confidence regarding the justification of the initial study design, it did bring about a feeling of apprehension: unlike in my clinical work, I only had one opportunity to deliver this research project. If the results were to be orientated towards establishing improvements in future research, I would not be able to go about immediately trying to develop this research myself. This was a potential source of frustration, as I was keen to provide something of value to the research and clinical domains as I found this intrinsically more motivating than fulfilling the requirements of a doctorate (see above).

Once the study design was complete the next significant stage of the project was achieving ethical approval. Filling out the forms for this felt like a long and tedious process. It felt like a lot of repetition and stating the apparent was occurring. However over time I learnt that what I thought was 'learning to state the obvious or minute details' was actually important development of skills in being able to communicate a complicated Clinical Psychology research project to a range of people from different backgrounds including laymen. I learnt to appreciate that with a research budget and the recruitment of many participants who were going to take part in the research project this was a vital process in order to ensure the integrity of my study. I believe the initial frustration may have been influenced by the fact that my previous experience of research projects were a lot more informal as they had been carried out at

undergraduate and A-Level. I had to attend my ethics committee meeting without my supervisor, which felt very intimidating as I had nobody to 'fall back on' in a very unfamiliar situation. Though it was anxiety-provoking being 'examined' from an ethical stance on my research project, this experience was helpful to improve my understanding of my own research project, my comfort in being able to explain and justify it to others, and I hope it will have been good preparation for my viva.

Recruitment

The recruitment phase of the project provided my first major source of stress with this endeavour. At the turn of December 2011, I was low on participant numbers, my main source of recruitment had fallen through, and I was entirely convinced that not only was I going to not achieve my desired number of participants but I was not even going to be approaching half of that figure. It meant that I had to invest a lot of time attending Alzheimer's society events and community cafés, sometimes having to set aside a whole afternoon at a time, and travelling long distances in order to just identify 'potential' participants. This initially escalated my stress; it felt like the more time I spent attending these types of events, the less time I spent actually data collecting. Supervision was extremely useful at this time, but also the support I received from the Carers Centre in Hull and the often familiar and always friendly faces who I encountered wherever I went to recruit. 'Pushing' my research project was something I felt incredibly uncomfortable with (which was another contributing factor towards wanting to do a research project which would hopefully be of real benefit) but I was surprised to rarely ever feel like this was what I was doing due to how obliging and enthusiastic people were about my project. It got to a stage where it felt like I must have met every single spouse of family member of someone with dementia in the local area (though I know this not to be the case), and it was a community who I felt very privileged to have got to know so well.

Data Collection and Interviewing

I aimed to conduct 59 interviews in order to achieve an ideal power level for my study. About 12 interviews in, it dawned on me just what a time-intensive objective this was: to drive out to participants, carry out introductions, conduct the interview and debrief as appropriate. Again, I was very humbled by

participant's enthusiasm and willingness to help with my research project. I really do not know how I could have remained dedicated to a project for so long without their contagiously passionate approach. I remember in earlier interviews feeling almost 'fraudulent' given my relative lack of experience in conducting this type of research. My first participant said to me something along the lines of: "I'll take your lead, you're a lot more experienced in this than I am". I remember thinking how ironic this was, as being my first participant, they had exactly the same amount of experience with the interviewing component of my study as I had. I think the most significant personal difficulty encountered in association with my role as a researcher was having to abandon my clinical approach and natural desire to contain and work with people's distress, which sadly but quite understandably did present during some interviews. It felt at times there was a parallel process whereby the caregivers sometimes seemed like they were in a helpless position and were in need of being ideally cared for. It felt very difficult to not be able to provide this care. Over time and with greater experience, I became a lot more comfortable with my role as a researcher. I hope that this meant that participants also felt increasingly comfortable being interviewed by me and taking part in the project.

Results

Following the passionate approach to my project often adopted by participants and their expressed interest in finding out the results of the study, I put a lot more pressure on myself to find something of merit within the study. It felt very frustrating to not be able to retain the hypotheses of the empirical study. I had to work through this frustration in order to understand why evidence had not been found for the model tested, and to be able critically evaluate the project so that future work may benefit from this and overcome the limitations of my study. I hope that future research will be carried out within this area, and it would be extremely interesting and important to find out which Psychological models can be used to better understand the family caregiver process when providing support for someone with dementia. Currently this appears to be an area which is growing exponentially within the clinical context, and I believe it is difficult to overstate the importance of their being an associated growth in research in this area in order to help inform how to improve the support provided for carers, which should in turn improve the support received by the care-recipient. I do

wonder how future research can overcome the problem of measuring propensity to help, particularly considering potential social desirability bias. I believe that this study reveals the importance of reconsidering the operationalisation of this concept, and should not serve as a barrier to future research in this area.

Systematic Literature Review

The systematic literature review demanded a very organised, structured and thorough approach; more so than any work I had previously engaged in. It felt like this increased the demand of the task and at times almost as if there was a 'correct' literature review out there which I had to achieve. Throughout the process of writing the review, it felt difficult to maintain a sense of personal achievement whilst writing it. I found it difficult to write a piece of work that, if conducted appropriately, I felt would be essentially the same as if somebody else had carried out the same review at the same time. I feel like it was very important to receive the encouragement that I did in supervision to carry out a more sophisticated synthesis of the results of this component of the thesis than I had first drafted, as this helped give me the sense of achievement I feel I would have been finding hard to gain otherwise. I hope that the way I reported the findings of the review can contribute to understanding of the wellbeing of family caregivers of individuals with dementia within the literature. Personally, I believe the experience of my approach taken to the systematic literature review has already benefitted my clinical work. It has improved my ability to critically evaluate papers, in particular their quality and how this impacts upon what conclusions may be drawn. This has helped when considering the evidence-base for interventions with clients, as rather than just searching to see if there is a paper in support of a particular intervention, I am now a lot more critical as to whether the study was valid and reliable enough to provide trustworthy evidence of effectiveness or efficacy. A particularly rewarding reflection was that I found myself engaging in this process whilst on clinical placement without planning to do so beforehand. It is a skill which I have realised I should further develop in order to improve my competence as both a therapist as well as a researcher.

Approach to Research

As stated above, I do sometimes struggle with scientific rigour if I feel like it could detract from the creativity I can have with a piece of work. This was present in the writing up of aspects of the systematic literature review, preparation for the submission to the Research Ethics Committee and at times when interviewing participants. Ultimately, with the help of my supervisor, this means that the finished product of a thesis is something that I have been able to feel proud of; that I have achieved a piece of scientific research. At times it felt like this was something that I was not capable of as I have a very 'verbal' approach to things. Another significant challenge was planning when particular components of the thesis should be completed by in order to meet the deadline for the thesis whilst managing the other demands of the Clinical Psychology doctorate. I have previously always focussed on getting one thing done at a time, but doing a thesis meant that I often had to be carrying out a number of tasks concurrently. Again, the use of supervision helped with this process. I did however find some of the more frustrating or anxiety-provoking times of the process to be when I felt out of control of an element which may affect either a deadline or the content of my thesis. For example, making amendments to my ethics application, difficulty fulfilling the desired quota of participants through planned routes and delays in the write-up process were all experienced as relatively stressful events during the production of this thesis. I felt that reflecting on the fact that this in part came from a place of feeling out of control helped to understand this stress and (combined with a problem-solving approach) eventually reduce it. Appreciating that all professionals conducting research encounter this problem and it is all part of the process helped, and is something I will be mindful of when engaging in future research.

Summary

Overall, this has been a very rewarding as well as challenging thesis to undertake. I believe dementia to be an even more important topic to explore than when I first started, and in particular, the processes spouse and family members go through when supporting those diagnosed with dementia. I feel that my approach to research has matured and developed such that I would feel a lot more confident in future projects. I think the thesis has also increased my ability to tolerate uncertainty and work with perceived pressure when things do

not go to plan. Finally, there have been a number of clinical implications that I will take from this research project, particularly in terms of critical evaluation which I can bring to my evidence-based practice. However the lasting impression I will have of this thesis is the inspiration and passion inspired in me by those who took part. And for that I am grateful.